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The Voluntary Health Sector: Looking to the Future of Canadian Health Policy and Research Part II

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Health Policy Research
Working Paper Series

The Voluntary Health Sector: Looking to the Future of Canadian Health Policy and Research Part II

Foreword

Canadians rely on and believe in the voluntary health sector. Voluntary health organizations build on the contributions of time and money of millions of Canadians to provide services in our communities, carry out research, advocate for improvement and raise funds, all in order to improve the well-being of Canadians across every population group and against every risk to health. They also build community capacity by involving Canadians as volunteers.

A majority of Health Canada's policy and program partners are voluntary organizations, and a substantial proportion of departmental expenditures is invested in the voluntary sector. While we know about the effectiveness of individual programs and organizations, there is little quantitative or qualitative evidence about the voluntary health sector itself. Because it is a key partner, we want to advance our understanding of this important subsector of what Prime Minister Jean Chretien has called the "third pillar" of society.

The important contribution of the voluntary sector to the health of Canadians highlights the need for a comprehensive body of research on its role and impact in Canadian communities. Recognizing this, the Voluntary Sector and Strategic Frameworks Unit, Population and Public Health Branch, commissioned a number of research papers, collectively called the Voluntary Health Sector Working Papers 2002. The research contributes to the understanding of the unique knowledge, perspective and expertise of Canada's voluntary health sector and its important place in Canadian life.

The papers address knowledge gaps in government, academia and policy circles in Canada and internationally. They also complement other current Health Canada and federal government initiatives to improve the delivery of health services to Canadians and to strengthen partnerships with the voluntary sector.

Health Canada would like to thank the authors of these papers and the organizations with which they are affiliated for their generous contribution to increasing our understanding of the vital part the voluntary health sector plays in maintaining and improving the health of Canadians. Thanks also go to Mary Jane Lipkin, Manager of the Voluntary Sector and Strategic Frameworks Unit, and to Karen Hill, Senior Analyst, for bringing these papers to publication.

Amanda Cliff
Director General, Strategic Policy Directorate
Population and Public Health Branch, Health Canada

Résumé (partie II)

C'est dans le cadre de l'Initiative fédérale sur le secteur bénévole et en conformité avec son engagement de promouvoir l'acquisition de connaissances et la recherche que Santé Canada a publié le recueil *Secteur bénévole de la santé – Documents de travail 2002*. Toutes les études qui y figurent apportent les premiers éléments d'une somme de connaissances sur le rôle et les responsabilités du secteur bénévole de la santé au Canada. À ce titre, elles aideront à susciter un intérêt pour l'élaboration d'un programme de recherche sur le secteur bénévole de la santé et à son intention. Elles façonneront l'élaboration des politiques et des programmes dans les secteurs public et bénévole, et, nous l'espérons, inciteront les chercheurs à poursuivre leurs travaux dans cet important domaine.

Les parties I et II renferment les versions abrégées des études parues dans *Secteur bénévole de la santé – Documents de travail 2002*. La partie I regroupe les études basées sur des sources statistiques, notamment l'Enquête nationale sur le don, le bénévolat et la participation. Celles de la partie II portent sur un vaste éventail de sujets de recherche. La version intégrale de toutes les études est disponible sur le site Web du Bureau du secteur bénévole, Centre de développement de la santé humaine, à **www.hc-sc.gc.ca/hppb/secteurbenevole/connaissances/documents_travail/index.html**.

Le cancer du sein est un grave problème de santé pour les Canadiennes. Dans **« De la détection au rétablissement et au-delà : la réponse du secteur bénévole de la santé aux besoins liés au cancer du sein »**, Femida Handy, professeure à l'Université York, et Christine Smith, de la Fondation canadienne du cancer du sein, établissent un cadre d'évaluation des organismes du secteur bénévole de la santé en se fondant sur un relevé des organismes bénévoles de la santé de la région de Toronto offrant des services relativement au cancer du sein. Les auteures ont recours à un personnage fictif composite pour présenter sous forme narrative les résultats de leur enquête sur les rapports qu'ont les femmes atteintes du cancer du sein avec les organismes du secteur bénévole de la santé.

Dans **« Un inventaire des recherches antérieures sur le secteur bénévole de la santé au Canada »**, Arslan Dorman présente les résultats d'une recherche documentaire sur les résultats de recherche publiés au sujet du secteur bénévole de la santé. Une définition large du secteur bénévole de la santé, une plage temporelle relativement étendue, et un regroupement des résultats en fonction de catégories de publications — revues, livres, actes de conférences, mémoires et thèses, et articles de journaux et de magazines — ont permis à M. Dorman de dégager les tendances en matière de publication.

Dans **« Recensement des organismes bénévoles prestataires de services de santé et de services connexes dans deux localités albertaines »**, B. E. Williams et Jill Finley examinent les organismes bénévoles qui offrent des services de santé et des services connexes dans deux localités du sud de l'Alberta, l'une urbaine (Lethbridge) et l'autre rurale (Taber). Dans l'ensemble, les résultats n'ont pas fait ressortir un modèle unique ou discernable qui aurait permis aux auteurs de conclure que les deux localités à l'étude différaient fondamentalement quant aux types d'organismes ou de services. Leur recherche laisse supposer que les activités de la plupart des organismes répondent à une demande ou à un besoin de services.

L'étude de Judy Birdsell, **intitulée « Les organismes bénévoles du secteur de la santé : un programme de recherche à définir »**, expose ce qu'il faut faire pour bien comprendre le

rôle et la contribution du secteur bénévole de la santé dans la prestation de la gamme complète des services de santé, de la promotion de la santé et du mieux-être jusqu'aux soins palliatifs. Son analyse de la nature et de l'éventail des rapports organisationnels dans lesquels s'inscrivent les interactions du secteur bénévole de la santé et du système formel de santé, et l'influence du premier sur le second, contribue également au portrait du secteur bénévole de la santé qui se dégage des travaux d'autres chercheurs canadiens.

Dans « **Le secteur bénévole de la santé : les intégrateurs des domaines de la santé** », Marguarite Keeley et Karen Hill examinent comment les centres de santé communautaires bénévoles assurent le lien entre les patients et les collectivités, les praticiens, les éducateurs et les décideurs dans différents dossiers du domaine de la santé. Cette étude résume les orientations stratégiques, définit et décrit le secteur de la santé et ses enjeux actuels, et répond à certaines questions d'importance, par exemple la pertinence, dans la réforme des soins de santé primaires, des organismes comme les centres de santé communautaires, qui sont non seulement des fournisseurs de soins primaires, mais des organismes bénévoles, multidisciplinaires, responsables auprès de la collectivité, et axés sur la prévention et la promotion de la santé. Les auteures concluent que, bien que le rôle du secteur bénévole de la santé dans le système public de santé au Canada n'ait pas été articulé, l'adoption du modèle des centres de santé communautaires contribuerait probablement à l'atteinte de plusieurs des objectifs visés par la réforme des soins de santé.

« **Le secteur bénévole de la santé : promoteur efficace du financement de la recherche en santé** », par Elinor Wilson, agente scientifique en chef à la Fondation des maladies du cœur du Canada, met en lumière le rôle de promotion des intérêts qu'ont réussi à jouer récemment les organismes du secteur bénévole de la santé. Après un aperçu théorique de la promotion des intérêts et un examen du retard pris par le Canada à la fin des années 1990 quant aux sommes consacrées à la recherche en santé, l'auteure relate comment la promotion des intérêts par les organismes de bienfaisance du secteur de la santé a abouti à des résultats concrets dont bénéficiera la population canadienne. Elle décrit en particulier le rôle qu'ont joué le Conseil canadien des organismes bénévoles en santé et le Conseil pour la recherche en santé au Canada. L'étude fait état, en conclusion, des enjeux et des questions qui méritent d'être approfondis.

Executive Summary (Part II)

As part of the federal Voluntary Sector Initiative, and in keeping with its commitment to knowledge development and research, Health Canada has published Voluntary Health Sector Working Papers 2002. Each paper in this collection contributes to the beginnings of a body of knowledge about the role and responsibilities of the voluntary sector in health in Canada. As such, these papers will help build interest in the development of a research agenda about and for the voluntary sector in health. They will inform policy and program development in the public and voluntary sectors and, it is hoped, spark further research efforts into this important sector.

Parts I and II include the abridged versions of some of the papers in Voluntary Health Sector Working Papers 2002. Part I focusses on papers that draw on statistical sources, including the National Survey of Giving, Volunteering and Participating, and Part II includes papers about a broad range of research interests. The full version of all papers is available at the Voluntary Sector and Strategic Frameworks Unit, Population and Public Health Branch, website (**http://www.hc-sc.gc.ca/hppb/voluntarysector/knowledge/working_papers/index.html**).

Breast cancer is a serious health concern for women in Canada. In **"From Discovery to Recovery and Beyond: The Voluntary Health Sector's Response to Breast Cancer"**, York University professor Femida Handy and Christine Smith of the Canadian Breast Cancer Foundation use a scan of Toronto-area voluntary health sector organizations associated with breast cancer to offer a framework to assess the impact of voluntary health sector organizations. The authors use a fictional composite character to present in narrative form the results of their investigation into how women with breast cancer choose to interact with voluntary health sector organizations.

In **"An Inventory of Past Research on the Voluntary Health Sector in Canada"**, Arslan Dorman presents the results of a quantitative search of published research findings on the voluntary health sector. By using a broad definition of the voluntary health sector and a generous time frame, and by classifying his results into publication categories—journals, books, conference materials, dissertations and theses, as well as newspapers and magazines—Dorman sheds light on publishing trends.

In **"An Inventory of Voluntary Organizations Providing Health and Health-Related Services in Two Alberta Communities"**, authors B. E. Williams and Jill Finley examine voluntary organizations that provide health and health-related services in two communities in southern Alberta—one urban community (Lethbridge) and one rural community (Taber). There was no unique or discernible pattern in the results that would allow the authors to conclude that the two communities were fundamentally different in the types of organizations that exist and in the types of services provided. The research suggested that the majority of organizations are driven by demand or need for services.

Judy Birdsell's study is entitled **"Voluntary Organizations Within the Health Sector: Toward a Research Agenda."** This paper discusses what needs to be done to understand the role and contribution of the voluntary health sector in service delivery across the spectrum of health services—from health promotion and wellness to palliative care. Her examination of the nature and range of organizational relationships through which the voluntary health sector interacts with and influences the formal health system is also a contribution to the emerging picture of the voluntary health sector being drawn by other Canadian researchers.

In **"The Voluntary Health Sector: Integrators Across Health Domains"**, authors Marguarite Keeley and Karen Hill examine how voluntary community health centres (CHCs) act to bridge and connect patients, communities as a whole, practitioners, educators and policy makers around health issues. Their paper summarizes policy directions, defines and describes health and current health issues, and provides responses to a number of important questions—for example, what is the relevance for primary health care reform of the CHC model of organizations that provide primary health care services but are also volunteer-driven, multidisciplinary, accountable to the community, and focussed on prevention and health promotion? The authors conclude that although the role of the voluntary health sector in Canada's publicly funded and publicly administered health system has not been articulated, the CHC model appears to meet many objectives of health care reform.

"The Voluntary Health Sector: Successful Advocates for Health Research Funding", by Elinor Wilson, Chief Sciences Officer with the Heart and Stroke Foundation of Canada, highlights the recent successful advocacy role played by health charities in Canada. After presenting background theory on advocacy and demonstrating how Canada's health research expenditures were lagging behind in the late 1990s, Wilson's paper tells how health charities used advocacy to achieve real results for the benefit of Canadians. In particular, the roles of the Health Charities Council of Canada and the Council for Health Research in Canada are described. The paper concludes with issues and questions for further study.

The Authors

Judy Birdsell is the principal consultant with On Management Limited in Calgary, Alberta. Her areas of focus include organizational analysis and strategy in the health, non-profit and health research domains, with particular interest in interorganizational relationships, organizational performance and research utilization. She also has a 20-year history of volunteer involvement in the health non-profit sector, including roles as chair of the boards of the Canadian Cancer Society, the Canadian Breast Cancer Research Initiative and the Stem Cell Network. Judy has a BSc in nursing, an MSc in health care research and a doctorate in organizational analysis.

Arslan Dorman's primary research interests are international political economy and Canadian public policy. He has been an associate of the Centre for Voluntary Sector Research and Development at Carleton University since 2001 and has done research on the voluntary sector for the Centre.

Jill Finley is a graduate student in the Faculty of Management at the University of Lethbridge in Alberta. Jill is a graduate of the bachelor of commerce program at McGill University. Prior to commencing graduate studies, Jill worked for several years in the energy sector in Ontario and the North. She understands community relations through her work as a volunteer and as a professional. Recently, Jill and a group of concerned citizens in Inuvik formed the Inuvik Recycling Society to raise public awareness and effect positive social change.

Femida Handy, PhD, teaches economics at the Faculty of Environmental Studies at York University in Toronto. Her award-winning research on the non-profit sector has been published in many leading journals and various other practitioner-oriented publications. Her area of interest includes a variety of issues related to the non-profit sector: volunteers, fundraising, entrepreneurship, wages, advocacy and issues of trust and reputation.

Karen Hill has worked since 1999 as Senior Analyst in the Voluntary Sector and Strategic Frameworks Unit, Population and Public Health Branch, Health Canada. Prior to this, Karen worked in several federal departments, building on 20 years of professional experience in voluntary sector social planning organizations. She also brings to her work substantial volunteer leadership experience in both Canada and the United States, and has published numerous articles about issues of interest in the voluntary sector.

Marguarite Keeley has been the Executive Director of Centretown Community Health Centre in Ottawa since January 2000. Prior to that, she was a senior manager in Health Canada's Medical Services Branch, and was responsible for the early development and implementation of the transfer of control of community health services to First Nations. Before coming to Ottawa to complete a master's degree in public administration, Marguarite worked in community recreation in North York, followed by six years as a community coordinator for the Etobicoke Social Planning Council.

Christine Smith has been a community volunteer for the past 15 years. Christine has been involved with the Canadian Breast Cancer Foundation since 1989. She served as Chairperson of both the Ontario chapter and national board of the Foundation from 1996–1998. She lives in the Toronto area with her husband and two children.

B. E. (Bernie) Williams, PhD, is assistant professor of organizational studies in the Faculty of Management at the University of Lethbridge in Alberta. He has conducted research on voluntary sport organizations, and on both voluntary and career organizations for fire and emergency medical services. His current research interest is the exploration of alternative organizational models for the delivery of health care and health related services.

Elinor Wilson, PhD, is currently Chief Science Officer at the Heart and Stroke Foundation of Canada. She is also the Co-chair of the Conference of Principal Investigators of the Canadian Heart Health Initiative, a member of the International Dissemination Committee for the Victoria Declaration, a member of the Ministerial Advisory Committee on Tobacco Control, Chair of the Framework Convention Alliance, President of the InterAmerican Heart Foundation, and Vice-President Elect of the World Heart Foundation. Elinor has an RN degree and a BA from the University of Manitoba, a master's degree in health sciences from McMaster University, and a PhD from Walden University in Minnesota.

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1. From Discovery to Response and Beyond:

The Voluntary Sector's Response to Breast Cancer

Femida Handy
York University

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Canadian Breast Cancer Foundation

Introduction

Given that in Canada alone more than one in nine women will be diagnosed with breast cancer and many will die,[1] it is no surprise that breast cancer has become one of the most serious health concerns facing all women. Today, millions of women are either living with breast cancer or have a close relative who is. What makes this scenario even worse is that the cause of breast cancer is not known and therefore it cannot be prevented.

Although breast cancer is not a new disease, what is relatively new is the response of the non-medical profession, which is becoming active in promoting and advocating for its prevention and cure. In particular, many voluntary sector organizations and individual volunteers have targeted the prevention, treatment, and cure of breast cancer as the focus of their efforts and funds. They do this through a gamut of actions, including raising public awareness, organizing support groups, counselling, disseminating information, advocating for change in policies, and funding and conducting research. At the macro level, they have been successful in raising the disease's profile in society—bringing about important changes in the ways government and other organizations expend public money for breast cancer research—and in assisting women with breast cancer and their families. At the micro level, they have helped hundreds of survivors with their emotional and physical needs in a variety of ways, ranging from providing information to forming support groups to assisting with hair loss and physical changes resulting from treatment.

The organizations that are of interest in this study are a subset of those organizations that are designated "charitable" organizations by the Canada Customs and Revenue Agency. The charitable sector (often referred to as the non-profit sector) consists of a variety of organizations, of which "health organizations"[2] constitute 5 percent of the total number of organizations and received 8.8 percent of total revenues in Ontario in 1997. The revenues came from government grants and payments (58 percent), earned income (23 percent) and private giving (19 percent) (Hall and Macpherson, 1997).

It is common practice to refer to this group of organizations as voluntary health sector (VHS) organizations, as we do in this report. Of interest in this study is the subset of VHS organizations that deal with various aspects of breast cancer.

The purpose of this research report, then, is to examine the response of VHS organizations to breast cancer, to propose a set of measures to examine the impact of VHS organizations in this area, and to offer a framework to assess this impact.

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1 *Canadian Cancer Statistics 1997*. Toronto, Canada: National Cancer Institute of Canada.

2 Health organizations include organizations dealing with a variety of issues related to health, including research and education, but exclude hospitals and universities.

What is Available to Mary?

Methods

What are the resources available to a woman who discovers that she has breast cancer? To answer this question, we surveyed 15 women and gathered information on their experiences as they moved from the discovery stage to the recovery stage and further. As a conceptual framework, we took a fictional individual, whom we named Mary, to provide an insight into the role VHS organizations play in a woman's life as she confronts breast cancer. We narrated Mary's experiences as she moved through various stages in her life after being diagnosed with breast cancer.

The 15 women chosen for interviews were those who reached out for treatment and recovery to organizations in the Greater Toronto Area. Some of them lived in the city of Toronto and others in the suburbs of Toronto. However, most of the women we interviewed were treated medically in Toronto hospitals and reached out to voluntary sector organizations in and around the Greater Toronto Area. Thus, the city and suburbs of Toronto provided this research with its spatial boundaries, and were the main repository of voluntary sector organizations reported in this study.

In many cases, the women in our sample were approached by VHS organizations as part of the organizations' outreach program. However, some had volunteered with VHS organizations prior to their experience with breast cancer. Most of them had picked up information regarding breast cancer from materials put out by VHS organizations. The organizations that our fictional character contacts are real.

The initial contacts for our interviewees were made through the Canadian Breast Cancer Foundation. We relied on a snowball technique, getting names of women breast cancer survivors through word of mouth and from connections with survivors who volunteered in a variety of voluntary sector organizations. Our own personal networks provided additional names.

As we did not try to represent the story of a "typical" survivor, we were not interested in finding interviewees from whose stories we could generalize to the population of survivors. Our aim was to interview survivors whose reach to voluntary sector organizations would cover the breadth of VHS organizations available in the region of our study. For this reason, we interviewed women from different socio-economic and ethnic backgrounds to ensure we would uncover voluntary sector organizations that cater to different types of survivors. Furthermore, we interviewed women who were at different stages on the road from "discovery to recovery" to ensure that newer and current VHS organizations would be covered.

As the interviews progressed, we noted an increasing overlap of organizations on our list and of those being offered by the interviewees. We continued our interviews until no new organizations were mentioned and we had reached saturation. In the last two interviews, we picked up no organizations that had not previously been uncovered by the interviewees or our own search.

Confidentiality parameters were provided and all the women read and signed the consent form provided. Many of the women eschewed the caveat of confidentiality offered to them and wished to be identified with their stories. However, in this research we had to decline their offer

because no one story gave us the full map of the reach of VHS organizations that the composite story provides. Their stories, nevertheless, were powerful and inspired us at all stages in the research; we were impressed with the impact VHS organizations had on their lives and how the survivors chose to continue their involvement with VHS organizations even after recovery.

Sample Characteristics

Fifteen women were interviewed for this study. They ranged in ages from 46 to 63, with an average age of 54. Seven women had discovered their breast cancer through routine mammograms. Six women had found their breast cancer through self-examinations. Only two women had discovered their breast cancers at routine physical examinations by their general physicians. The time from discovery to recovery and beyond for all these women ranges from one year to 19 years.

All but two survivors had their initial surgical intervention at hospitals in Toronto; two were treated in Richmond Hill, a suburb of Toronto. All but one survivor underwent either radiation or chemotherapy at two Toronto locations: Princess Margaret Hospital or Women's College Hospital.

Several survivors in our sample had significant and protracted interactions with voluntary organizations. In many cases, survivors volunteered at VHS organizations related to breast cancer in their recovery stage. Several took leadership roles, although in one case this had happened prior to the onset of the disease. We had a few cases in which survivors shunned all interaction with VHS organizations and only dealt minimally with VHS organizations at the venues where they underwent treatment. Two relied heavily on Internet sources for support and information originating within and outside Canada.

While the focus of the study is formal VHS organizations, our sample of survivors, in the majority, relied heavily on the informal networks of friends and family for support and information. Many informal ties through, for example, places of worship, book clubs, neighbourhoods, car pools and volunteers in hospitals offered invaluable assistance. It did not seem that this assistance was a substitute for the kind of support available through VHS organizations; nevertheless, it remains an important and natural resource for nearly all survivors on their road to recovery and cannot be underestimated. The scope of our research does not allow us to account for the informal systems that nearly all women in our sample relied on for support, albeit at different levels.

Mary's Story

I had read about breast self-examinations in my local newspaper and had been doing them monthly for almost a year. In January, I discovered a lump in my breast. I tried to ignore it but a nagging voice told me to do something. Later in the week, I phoned my general physician and the secretary gave me an appointment for early the following week. The thought of breast cancer did not leave me after securing the appointment. However, I decided not to cause any distress to my husband or children as I had no idea what the "lump" was going to be. Several of my friends had benign lumps and I hoped that mine would also be benign.

Instead of speaking to anyone, I checked out the website **http://www.cbcf.org** that was listed in a magazine article I had read that month. I found information on various aspects of

breast cancer, although some of it was premature for me. Later on, I went back to that website frequently for information and support.

At my appointment, my physician advised me that there was a cause for concern, but not to worry until we had more definitive information. She reminded me that often breast lumps are benign, but I would need a mammogram and ultrasound to rule this out. She gave me the phone numbers and a note to take with me when I went for the mammogram and ultrasound. The mammogram showed that the lump I had was suspicious. The physician informed me that there was a very high likelihood that it was malignant and made arrangements for me to undergo surgery. I was unprepared and in shock. Only later when I recovered from the shock of knowing I had breast cancer was I able to discuss the various options with my physician and surgeon.

In March, I underwent a lumpectomy and node removal. At this time, the Canadian Cancer Society helped me by providing a caregiver for my young daughter. As some of my nodes were involved, I needed chemotherapy and radiation treatment. Suddenly I wanted more information and although I got some information from my doctor, it did not seem like enough. I felt vulnerable and very depressed. At this time, there was a breast cancer survivor who came and talked with me about what she had been through and what I should expect. I found this very useful and supportive. Despite the family and friends who supported me through this illness, the support of a survivor was essential to me. She had been there and lived to tell the tale. I am not sure whether she was a hospital volunteer or had come from another organization.

During the early days of my treatment, I was contacted by a volunteer from the Reach to Recovery program and I attended two support group sessions. Volunteers from the Ontario division of the Canadian Cancer Society helped me by providing transportation when I needed to go for my treatments, and I am grateful for this assistance.

I then started more actively to research the disease through a variety of websites, links from the original website to sites such as those of the Canadian Breast Cancer Research Initiative and Canadian Health Network. On these and other websites I found out about the variety of treatments, and what breast cancer can mean in terms of life changes. This browsing of websites helped me to stay focussed on my illness without getting depressed.

In May, I underwent chemotherapy for six months and was offered support groups and information videos by the medical staff. At this time, I declined all this support. During my radiation treatment I was referred to the Look Good, Feel Better program. This was a wonderful program. I attended a workshop and learned how to look better, including new ways of putting on makeup and how to choose wigs. I not only received cosmetics but left with a renewed sense of self-confidence, control and hope. I also started to attend my local breast cancer support group. These sessions allowed me to share my concerns with other women and to listen to theirs. A level of camaraderie developed that nurtured me and helped me deal with the anger and helplessness I had felt since I had discovered my breast cancer.

When I felt better, I was determined to do some volunteering for breast cancer research. I have two daughters and felt the need to do something. I also wanted to volunteer as a way of giving back for the support I received from many VHS organizations along the way. The first opportunity came at the Run for the Cure. This annual event raises money for breast cancer research. I volunteered at the event and found it extremely rewarding. Many of my friends and family took part. Later that month, I approached the Willow Breast Cancer Support and Resource Service and offered to be a volunteer visiting other women diagnosed with breast cancer. Two

years later, I joined the Ontario chapter of the Canadian Breast Cancer Foundation and served on their education committee. At this time I found out about the dragon boat races. I joined other survivors and took part in a race. This was one of the activities I enjoyed very much as it helped to build my physical strength and gave me a goal to work towards—a great healing process for me emotionally!

My work with other women in breast cancer support groups is very valuable to me. It reminds me of the time I was experiencing great distress and needed support. It is a rewarding experience to be able to help other women during their time of distress. My primary interest in volunteering with the larger organizations was to raise the profile of breast cancer in the general public and to fundraise. This helped me as a survivor to overcome the feelings of being out of control and being alone in my fight with breast cancer. Although many of these VHS organizations exist to fund future research and offer ongoing support of breast cancer victims during their time of stress and need, they also provide an outlet for women to work together in the fight against breast cancer. By volunteering with these organizations, I felt I had really confronted my disease head on and taken positive steps in my journey to recovery.

Analysis

Mary's story identifies several interactions with VHS organizations along her road to recovery. Clearly the VHS organizations were instrumental at two levels: at the initial stages and in providing information and support for her physical and psychological well-being.

As with most women in our sample, Mary's reliance on the VHS organizations comes only after surgery, with the brief exception of the initial Internet search.

Mary is unusual in the number of contacts she made with VHS organizations; the average number of contacts made by our sample was 2.2 during treatment. Since this is not a representative sample, we cannot generalize to the population of survivors. Given our method of eliciting our sample, this number may be high, since we relied on VHS organizations to give us a list of names to work from.

Women in our sample, after their treatment stage, volunteered their time to an average of two VHS organizations related to breast cancer. Their volunteer activities ranged from fundraising by walking in the Run for the Cure to assuming leadership roles at large VHS organizations related to breast cancer. Again, this may not reflect the trend for the population. But one thing we learned was that such volunteering, for many of the women, enhanced their own sense of being in control of the disease by making a contribution to the fight against breast cancer. Many women also felt it was a way to give back the support they had received from other survivors acting in volunteer positions.

Unusual in our findings is that nearly all women only approached VHS organizations after surgery. It would be reasonable to expect that women who received a breast cancer diagnosis would reach out for information and support prior to making their decision on the nature of surgical (or non-surgical) intervention. With the exception of one woman who called the Canadian Cancer Society prior to surgery, none of the women had any contact with VHS organizations until after surgery, and usually only during chemotherapy or radiation therapy sessions. At this time they were approached by volunteers involved in outreach programs, or joined support groups with which they later had ongoing relationships.

During the time of intense stress, the time between diagnosis and surgery, it seemed unusual that there was no VHS organization involvement. There was no outreach from VHS organizations, nor was there any effort on the part of women newly diagnosed with breast cancer to take advantage of the information and support available. At the time when important decisions are being made and the terms of reference for dealing with the disease are negotiated by each individual and her family, the only contact seems to be with the physician and surgeon. One caveat to this finding was the availability of information on the websites of many VHS organizations that were accessed by a couple of women in our sample. However, one woman remarked that the information available "was too much and too scary" at that early stage.

Framework for Analyzing the Impact of VHS Organizations

VHS organizations' impact occurs at two distinct levels. At the micro level, the impact is on women diagnosed with breast cancer and their families, as well as on women seeking information, prevention and screening. At the macro level, the impact is on research on prevention, screening, treatment and cure of breast cancer and advocacy in the policy arena. In both cases, VHS organizations play a major role and therefore have a direct and indirect impact on women with breast cancer and all other women who may be potential victims of breast cancer.

It is important to measure this impact at both levels so that resources can be directed to those efforts of which the impact is optimal. Government, the major funding source for VHS organizations, as well as private donors, need to know that resources diverted to VHS organizations (from other competing needs) are indeed making a positive impact on breast cancer at either the micro or macro level.

How do we measure this impact? It is well recognized in the literature that impact measurement is difficult in the realm of non-profit organizations, especially in defining one measure that is meaningful over the sector as a whole (Herman 1999). Very often goals of non-profits are not easily measurable, since they are often related to psychosocial outcomes and the enhancement of quality of life (Forbes 1998). In the case of VHS organizations related to breast cancer, measuring their impact is difficult.

Many organizations in our study have multi-pronged goals. The Canadian Cancer Society (CCS) is an example. The impact of the CCS must be judged on the basis of the eradication of breast cancer, and the enhancement of the quality of life of cancer patients. In the first instance, incidence and mortality rates related to breast cancer can help to measure the impact. Nevertheless, it would not be easy to isolate and measure the impact of the CCS. For example, even if the rates of incidence and mortality are decreasing, it would take careful study to establish how much of that decrease was due to the efforts of the CCS, other VHS organizations that share this goal, or environmental factors.

We note there exists a wide range of VHS organizations whose complete or partial focus is breast cancer. Their efforts include some combination of prevention, screening, treatment, enhancement of quality of life, outreach, support, education, information dissemination, research and community capacity building. Their aim is to aid all women who may be susceptible to breast cancer, those who are living with it, and their families and friends. Other organizations are involved with larger issues of networking, dissemination, research and advocacy. Many are

large, well-funded organizations; some are small grassroots organizations without any significant budgets. The question pertinent to our research is how to assess their impact on breast cancer at the macro and micro levels.

To do this, we analyzed the undertakings of VHS organizations involved with breast cancer at both the micro (patient) level and macro (disease and policy) levels. After reviewing the VHS organizations in and around Toronto, and their stated missions, we did a content analysis to elicit the dimensions through which impact may be assessed. We arrived at eight fairly distinct dimensions; not all dimensions are relevant for all organizations, since they have different missions and goals. The dimensions were chosen by selecting the top eight that appeared with the highest frequency in the mission statements (or equivalent) of the VHS organizations in a compiled inventory of these Toronto-area organizations.

The dimensions given below are not mutually exclusive, but have been separated for the purposes of this analysis. The dimensions along which impact can be assessed are as follows.

1. Prevention
2. Diagnostic and screening
3. Treatment and therapy
4. Quality of life (psychosocial support for cancer patient, family and friends)
5. Dissemination of information
6. Education and awareness
7. Research on screening, treatment, prevention and cure
8. Policy advocacy

Assessing impact is difficult for most of these dimensions. We are forced to conclude that to measure the overall impact of VHS organizations on breast cancer we must rely on a small number of fairly easily measured indicators, such as size (revenues and resources), distribution, number of clients served, incidence of disease and mortality. These impacts are divided into the following four categories.

A. Supply
B. Demand
C. Comparative data (regional comparisons on incidence, survival and mortality rates)
D. Impact effects of government spending

We suggest the following framework for assessing the impact of VHS organizations on breast cancer.

A. Supply

1. Map of the VHS organizations dealing with breast cancer—number, type, size and age—as well as their distribution into regions with differing access. (Regions are defined for the purposes of comparison in numbers 6 and 7.)

2. Monetary and non-monetary resources used by organizations in number 1 while pursuing their mission. For organizations with several goals, these resources should reflect only those targeted at breast cancer. These figures are obtained from annual reports and budgets and statistics on volunteer usage (in hours).
3. Take into account flows of revenues within organizations in the VHS to exclude double counting.

B. Demand

4. Compile figures for the number of clients served by the organizations in number 1 for the regions under study.
5. Using survey methods, determine in each region the average number of VHS organizations a typical woman with breast cancer uses for her own needs and volunteers with.

C. Comparative data

6. Note the incidence and mortality rates from breast cancer and the distribution of different types of VHS organizations for each of the regions.
7. Determine, using appropriate survey methods, the morbidity among women with breast cancer in regions where there is greater access to support systems offered by VHS organizations and regions where there is a distinct lack of such support.
8. Compare usage and accessibility variations over regions.

D. Effects of government spending

9. Determine expenditures made directly and indirectly by government on the various facets of breast cancer (medical insurance programs, infrastructure expenses, etc.) and assess the relative share of the VHS organizations' contribution to breast cancer.
10. Assess the burden that would be shifted to the government-financed medical system if government funding to the VHS organizations decreased.

The framework suggested above is limited and uses proxy measures for the impact, particularly in the areas of research and advocacy. However, this is a beginning. We hope that this study will invite further research to measure the impact of VHS organizations, as well as to fine-tune of this framework or develop other more suitable measures of impact.

Conclusion

In this report, we examined the response of VHS organizations to breast cancer. They are active in promoting research, engaging in advocacy and disseminating information and raising awareness at the macro level. At the micro level, they help survivors by providing assistance, information, counselling and support groups, all aimed at enhancing quality of life for women with breast cancer and their families.

We followed Mary through her journey from discovery to recovery and beyond. We noted her involvement with VHS organizations and thereby confirmed the importance of these organizations in the lives of women with breast cancer and their families.

Our data reveals a finding worth pursuing: the lack of VHS organization involvement during the time between diagnosis and surgery. It seems unusual that there was no VHS organization involvement at this time of intense stress, when women appear to be looking for support and information to help them make their decision on which treatments to adopt.

We noted that there is much debate in the literature on measuring impact and effectiveness of non-profit voluntary organizations. In our particular case, it is further compounded by the fact that the VHS organizations are diverse and hence the impact of the services they offer at the micro or macro level (or sometimes both) cannot be easily integrated. Using the dimensions along which impact is meaningful for this diverse set of organizations, we proposed a range of measures to examine the impact in four categories. The four categories proposed examine the supply of the services, the demand for the services, comparative information on the impact of VHS organizations in terms of morbidity, mortality, and survival, and finally the impact of VHS spending as compared with government spending.

This framework is the first of its kind in assessing the impact of the voluntary sector on a particular health problem. Further research remains to be done to put flesh on the bones of the framework. This level of detail will reveal what can and cannot be done and at what cost. The framework may also be sufficiently generic to be adapted, with minor modifications, to other diseases.

The framework is limited in one important way: it cannot measure the depth of the impact on the lives of the women nor the effectiveness of advocacy and research undertaken except by using proxy measures of size and resources. Furthermore, it is also unable to account for the tremendous support and information available in informal networks. Nevertheless, it is a framework that we hope will initiate an ongoing discussion on the role of voluntary organizations and their impact on the health and well-being of Canadians.

Suggestions for Further Research

We have used the terms *impact* and *effectiveness* as they are commonly used in the literature. Is it necessary to redefine the impact of VHS organizations when dealing with breast cancer? We noted that the impact of these organizations is at two levels. The first level is the macro level—the impact on the disease through research and policy advocacy. The second impact is at the micro level—on women (and their families) who either have the disease or are likely to contract the disease. Is this two-fold division of impacts sufficient? Does impact measurement need to be more finely divided to get a better picture of the impact of VHS organizations?

We have suggested comparative assessment on incidence, mortality and morbidity rates across regions differentiated by access to VHS organizations. This is certainly meaningful at the micro level. Does this have an impact at the macro level? Does it matter where the research/ advocacy takes place?

Furthermore, to understand impact more fully it is necessary to understand what happens at VHS organizations over time. Longitudinal studies to assess the growth in the VHS organizations in the face of changing information on the disease and changes in responses to the various stakeholders (researchers, advocates, women with breast cancer, caregivers) will be required to give a more accurate picture of effectiveness and impact.

Also, what modifications are necessary to apply this framework to VHS organizations dealing with other diseases?

These are just some of the questions this study raises. Clearly, much more research needs to be done in this area.

Bibliography

Cameron, K. S. and D. A. Whetten. 1983. *Organizational Effectiveness: A Comparison of Multiple Models.* New York: Academic Press.

Cameron, K. S. 1986. "Effectiveness as paradox: Consensus and conflict in conceptions of organizational effectiveness." *Management Science* 32: 539–553.

D'Aunno, T. 1992. "The effectiveness of human service organizations: A comparison of models." In Y. Hasenfeld (ed.), *Human Services as Complex Organizations,* pp. 341–361. Calif.: Sage.

Davison, K. P., J. W. Pennebaker and S. S. Dickerson. 2000. "Who talks? The social psychology of support groups." *American Psychologist* 55: 205–217.

Degner L. F. et al. 1997. "Information needs and decisional preferences in women with breast cancer." *Journal of the American Medical Association* 277: 1485–1492.

Forbes, D. P. 1998. "Measuring the unmeasurable: Empirical studies of nonprofit organization effectiveness from 1977 to 1997." *Nonprofit and Voluntary Sector Quarterly* 27(2): 183–202.

Goodwin, P. J. et al. 2001. "The Effect of Group Psychosocial Support on Survival in Metastatic Breast Cancer." *The New England Journal of Medicine* 345(24): 1719–1726, December 13.

Gray, R. E., et al. 1998. "Information needs of women with metastatic breast cancer." *Prevention and Control* 2(2): 57–62.

Hall, M. H. and L. G. Macpherson 1997. "A Provincial Portrait of Canada's Charities" *Canadian Centre for Philanthropy Research Bulletin* 4: 2–3, Spring/Summer. Toronto: Canadian Centre for Philanthropy.

Handy, F. 2000. "How We Beg—The Analysis of Direct Mail Appeals." *Nonprofit and Voluntary Sector Quarterly.* 29(3): 287–302.

Heinz, L. 2001. *Voluntary Health Organizations in Canada: Public Involvement and Support.* Toronto: Canadian Centre for Philanthropy.

Herman, R. D. 1990. "Methodological issues in studying the effectiveness of nongovernmental and nonprofit organizations." *Nonprofit and Voluntary Sector Quarterly* 19(3): 293–306.

Herman, R. D. 1992. "Nonprofit Organization Effectiveness: At What, for Whom, According to Whom?" *Nonprofit and Voluntary Sector Quarterly* 21(4).

Herman, R. D. and D. O. Renz. 1997. "Multiple Constituencies and the Social Construction of Nonprofit Organization Effectiveness." *Nonprofit and Voluntary Sector Quarterly* 26(2): 185–206

Herman, R. D. and D. O. Renz. 1999. "Theses on Nonprofit Organizational Effectiveness." *Nonprofit and Voluntary Sector Quarterly* 28(2): 107–126.

Humphreys, K. and J. Rappaport. 1994. "Researching self-help/mutual aid groups and organizations: Many roads, one journey." *Applied and Preventive Psychology* 3: 217–231.

Kushner, R. J. and P. P. Poole. 1996. "Exploring structure-effectiveness relationships in nonprofit arts organizations." *Nonprofit Management and Leadership* 7: 119–136.

Meyer M. W. and V. Gupta. 1994. "The performance paradox." In B. W. Staw and L. L. Cummings (eds.) *Research in organizational behaviour,* pp. 309–369. Conn.: JAI Press.

O'Brecht, M. and J. Doutriaux. 1992. "Impact of the Private Non-profit Sector on the Distribution of Canadian Health Research Funding Source." *Canadian Public Policy / Analyse de Politiques* 18(3): 290–99.

Plantz, M. C., M. T. Greenway and M. Hendricks. 1997. "Outcome measurements. Showing results in the nonprofit sector." In K. E. Newcomer (ed.), *New Directions for evaluation, using performance measurement to improve public and nonprofit programs.* San Francisco: Jossey-Bass.

Riessman, F. and D. Carroll. 1995. *Redefining self-help.* San Francisco: Jossey-Bass.

Scott, W.R. 1995. *Institutions and Organizations.* Calif.: Sage.

Sheehan, Jr., R. M. 1996. "Mission Accomplishment as Philanthropic Organization Effectiveness: Key Findings from the Excellence in Philanthropy Project." *Nonprofit and Voluntary Sector Quarterly* 25(1): 110–123.

Spiegel, D., et al. 1989. "Effect of psychosocial treatment on survival of patients with metastatic breast cancer." *Lancet* 8668: 888–891.

Strasser, S., et al. 1981. "Conceptualizing the goal and system models of organizational effectiveness—Implications for comparative evaluation research." *Journal of Management Studies* 18(3): 321–340.

Tocher, M. 2002. *How to ride a dragon: Women with breast cancer tell their stories.* Toronto: Key Porter Books Ltd.

Williams, A. R. and C. Kindle. 1992. "Effectiveness of Nongovernmental and Nonprofit Organizations: Some Methodological Caveats" *Nonprofit and Voluntary Sector Quarterly* 21(4).

2. An Inventory of Past Research on the Voluntary Health Sector in Canada

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Introduction

This report assesses research on the voluntary health sector (VHS) in Canada. A broad-based index analysis resulted in collection of information on 101 journal articles, 26 books and manuscripts, 6 conference papers, 10 unpublished PhD dissertations and master's theses, and a sample of 7 newspaper and magazine articles that focussed on the VHS in Canada.

The main objective of the report is to classify the research findings in terms of publication categories. Within each category a further analysis of the subject of publication is undertaken. Subject analysis establishes a major analytical tool in terms of understanding the research gap that exists in the VHS in Canada, while at the same time presents an opportunity to develop sensible proposals to remedy the situation.

Aside from the subject analysis, the report provides a list of journals that researchers used as a venue to disseminate their research findings. The inventory of journals provides valuable information that could be used in guiding researchers who are commissioned to undertake research on VHS in Canada by a ministry of health or any other organization. Journals such as *Social Science and Medicine*, *Canadian Journal of Public Health*, *Canadian Medical Association Journal* and *Journal of Community Health* are important venues of publication that could be contacted during and upon the completion of commissioned work for publication.

The report also provides a sense of how the inventory of publications is compiled. Furthermore, the list of major indexes provides additional guidance for future analyses on VHS-related journal scanning as well as any other literature survey on the health sector in general.

The report concludes with a limited number of recommendations to further the study of VHS in Canada. Based on the observations of the analyst, such recommendations will mainly focus on creating and sustaining an academic research interest in the field as well as providing some practical guidelines.

The report is organized as follows:

- Summary of Findings;
- Subject Analysis: Analytical Issues—deals in both analytical aspects and numerical analysis;
- List of Publication Venues (specific to journal articles);
- List of Publication Indexes as Sources of Literature Scan;
- Conclusions and Recommendations.

A full list of publications is given in the Appendices (which are not included in this abridged version).

Summary of Findings

As noted above, this section presents a summary of literature scanning. Table 2-1 classifies publications on the VHS in Canada by type of publication, from 1971 onwards. A 10-year time frame is provided in order to get a better understanding of time distribution of past research on the subject.

Table 2-1: Classification of Publications (type/time frame)

	Time Frame				Total
Type	2000s	1990s	1980s	1970s	1971–2001
Journals	25 (25%)	65 (65%)	9 (9%)	2 (2%)	101 (100%)
Books	4 (15 %)	15 (58%)	4 (15%)	3 (12%)	26 (100%)
Conferences	—	3 (50%)	3 (50%)	—	6 (100%)
Dissertations/ theses	—	8 (80%)	1 (10%)	1 (10%)	10 (100%)
Newspapers/ magazines	—	7 (100%)	—	—	7 (100%)
Total	29 (19%)	98 (65%)	17 (11%)	6 (4%)	150 (100%)

Note: Percentages do not add up to 100 percent due to rounding.

Quick-Reference: Numbers

- Literature scan produced 150 publications in total.
- 67 percent of these publications are journal articles, 17 percent are books and manuscripts, 7 percent dissertations/theses, 5 percent newspaper/ magazine items and 4 percent conference papers.
- 65 percent of all journal articles were published in the 1990s, and 25 percent were published in the last two years. It seems to be the case that interest in the field is increasing. (Assuming that the level of publishing in the 2000s continues at the same rate, one can extrapolate that in the next eight years we can expect to see at least another 100 journal articles on the VHS in Canada.)
- The percentage of journal articles published in the 1990s is equal to the percentage of total publications published in the 1990s.

Figure 2-1: Distribution of Publications (type/time frame)

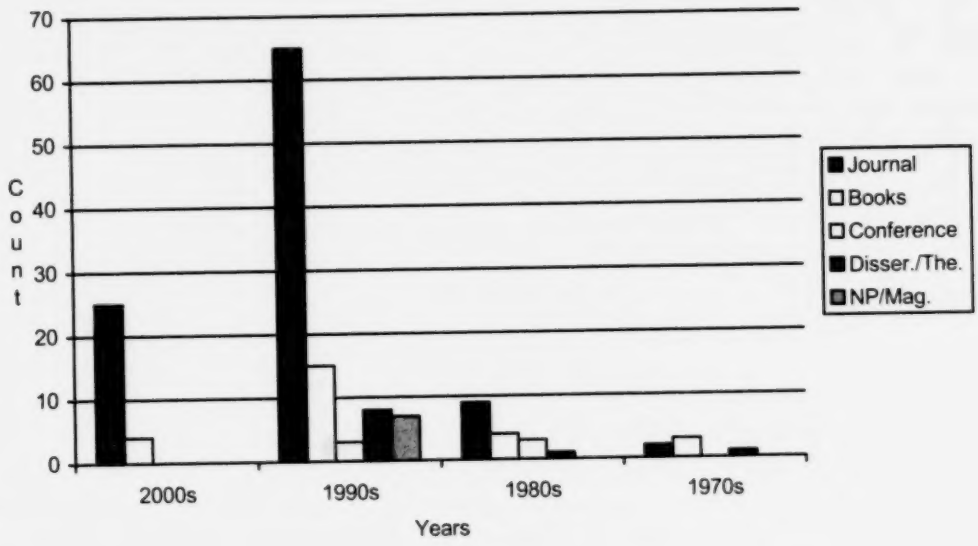
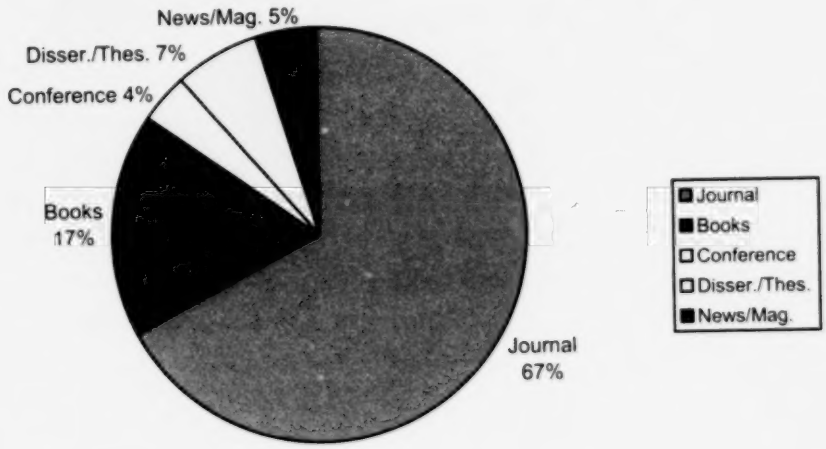


Figure 2-2: General Distribution of Publications



Subject Analysis: Analytical Issues

At an analytical level, subject analysis creates two main taxonomies: organizational dimension and functional dimension. Within the organizational dimension, this report classifies publications in terms of a) studies focussed on one or more of the general aspects of the VHS in Canada (VHSG), b) organizational case studies (OCS) and c) other VHS related studies (VHS-Rel). In a similar vein, the functional dimension attempts to classify the past research with respect to a) services and service delivery (S-SD), b) general policy related issues (GPRI) and c) health promotion and education (HPE).

Organizational Dimension

a) VHSG: Studies that focussed on one or more general aspects of the VHS are coded under this subcategory. Ranging from examinations of organizational aspects of community health centers to health sector reform specifically dealing with the VHS, many studies reflected upon at least one organizational aspect. Classification is generally based on the information provided in abstracts whenever available. In the absence of an abstract, the title and/or keyword information is used.

b) OCS: Organizational case studies were very common. Despite the fact that they provided some general information on the VHS, it is important to put case studies in a category of their own simply because of their scope and the limitations resulting from the methodological approach.

c) VHS-Rel: Some of the studies focussed on the health sector in general, with some attention to VHS. This subcategory reflects the fact that the relevancy was significant even though the study was not particularly dealing with the VHS as such.

Functional Dimension

a) S-SD: VHS literature often dealt with health services, and delivery of such services, by community health organizations. Covering outcomes measurement, effectiveness/efficiency evaluation, service history and dissemination of experience-based knowledge, many studies were in fact designed to produce knowledge on the basis of the functions of VHS organizations within the general frame of health sector in Canada.

b) GPRI: Often, researchers discussed a policy-related issue both in the sense of health policy and the role of VHS organizations, and particular managerial, financial and technical aspects of the functioning of VHS organizations. In this case, the functional dimension means that particular publications bring out a macro-functional aspect of the VHS in a general policy framework and a micro-functional aspect in terms of organizational policy-making.

c) HPE: This subcategory separates out studies that particularly deal with health promotion and education functions of VHS organizations, since such analyses provide a further functional dimension to the role of VHS organizations within the health sector in general.

Table 2-2 presents a numerical distribution of publications across the organizational dimension.

Table 2-2: Distribution of Publications: Organizational Dimension

Type	VHSG	OCS	VHS-Rel	Total
Journals	56 (55%)	39 (39%)	6 (6%)	101
Books	16 (62%)	6 (23%)	4 (15%)	26
Conferences	1 (17%)	5 (83%)	—	6
Dissertations/ Theses	7 (70%)	3 (30%)	—	10
Newspapers/ Magazines	1 (14%)	6 (86%)	—	7
Total	81 (54%)	59 (39%)	10 (7%)	150

Quick Reference: Numbers

- More than half of the publications focussed on at least one aspect of the VHS in general (54 percent). 39 percent of the publications were case studies that focussed on at least one organizational aspect of the VHS organization under review.
- 55 percent of the journal articles were focussing on VHS in general, 39 percent were case studies.
- Dissertations/theses were mainly dealing with general aspects of VHS organizations; this is surprising since such studies mainly focus on case studies, as they are more manageable in terms of time and financial restrictions in post-graduate education.
- A majority of books and manuscripts were confined to at least one of the general characteristics of VHS organizations. This may prove to be productive if further studies follow the same pattern, as books and manuscripts are more theory-oriented and there exists a major semantic confusion in classification and definition issues concerning the VHS.
- Most of the conference papers are case studies; this seems to be normal in this type of publication. Conference papers are generally limited in scope, and conferences are generally theme oriented.

Table 2-3 presents the classification of publications with respect to functional orientation.

Table 2-3: Distribution of Publications: Functional Dimension

Type	S-SD	GPRI	HPE	Total
Journals	48 (48%)	47 (47%)	6 (6%)	101
Books	14 (54%)	12 (46%)	—	26
Conferences	1 (17%)	2 (33%)	3 (50%)	6
Dissertations/ Theses	4 (40%)	6 (60%)	—	10
Newspapers/ Magazines	2 (29%)	4 (57%)	1 (14%)	7
Total	69 (46%)	71 (47%)	10 (7%)	150

Quick Reference: Numbers

- There seems to be an equal distribution among the publications in general with respect to functional aspects of services and service delivery (46 percent) and general policy related issues (47 percent).
- The distribution of journal articles follows the same pattern: services and service delivery, 48 percent and general policy-related issues, 47 percent.
- A majority of conference papers are related to health promotion and education; again, this is due to the nature of academic work related with conferences in general.
- 60 percent of all dissertations/theses are devoted to general policy-related issues. This is in line with the general trend in the organizational dimension, in which we observe a majority of such publications devoted to general issues.
- A majority of books and manuscripts focussed on services and service delivery (54 percent), closely followed by general policy-related issues (46 percent).

List of Publication Venues (specific to journal articles)

A list of journals is presented in Table 2-4 with specific reference to the number of publications published in respective journals. This list may provide a rough guide in terms of further research publications, as it presents a wide array of institutions that have published work on VHS in Canada so far. Only those journals that published at least two articles are included in the list. A complete list can be found in Appendix 1 (in the unabridged version of this paper), which presents the total inventory of journal articles.

Table 2-4: List of Journals

Name of the Journal	Number of Articles
Social Science and Medicine	8
Canadian Journal of Public Health	5
Canadian Medical Association Journal	5
Journal of Community Health	3
WE International	3
International Journal of Health Services	2
Public Health Nursing	2
Sociologie du Travail	2
Health Care Management Review	2
Health and Place	2
Community Mental Health Journal	2
Northern Ontario Business	2
Journal of Epidemiology and Community Health	2
Canadian Journal on Aging	2

There seems to be a wide variety of venues for academic/professional publication on the VHS in Canada. American academic journals have also published Canadian material (as presented in Appendix 1 of the full version of this paper). *Social Science and Medicine*, *Canadian Journal of Public Health* and *Canadian Medical Association Journal* deserve special attention. Researchers are advised to contact the editors of such journals, even during the initial phases of their research, to introduce the subject matter of the study and how it relates to the area in which the journal publishes material.

List of Publication Indexes as Sources of Literature Scan

The following are the major social science and science indexes from which the researcher compiled the inventory of past research on the VHS in Canada. The Institute of Scientific Information's Social Science Citation Index (SSCI) is one of the major sources of scientific information pertaining to humanities and social sciences in the world. The SSCI contained more than 7.5 million entries as of November 2001, covering the years between 1995 and 2001. The previous years (1971 through 1995) are covered in hard-copy indexes that can be found at any university library (in this case the Carleton University library). Gov-Info-Canadian Research Index (CRI) covered journal articles published from 1982 to 2001. Public Policy-PAIS International is a collection of public-policy-related material since 1972. Social Work Abstracts indexed publications in this area since 1977, and Canadian Business and Current Affairs-CRI covers Canadian-specific material published since 1982. These are some of the examples that should provide an understanding of the coverage of literature scanning.

The keywords and phrases that are used in scanning were provided to the researcher along with the project proposal. The list of items proved to be efficient in producing VHS-related publications as search outcomes.

The list of major indexes included:

- AIDSEARCH
- Cambridge Scientific Abstracts (CSA)
- Canadian Business and Current Affairs (CBCA)
- Canadian Research Index (CRI)
- CISTI
- Conference Papers Index
- CUBE (Carleton University Bibliographic Enquiry)
- EconLIT
- ERIC
- Gov-INFO (Sub-index of CRI)
- MEDLINE
- PAIS
- PsycLIT
- Public Policy PAIS International
- PUBMED
- Social Science Citation Index (SSCI)
- Social Services Abstracts
- Social Work Abstracts
- Sociological Abstracts
- Web of Science
- Wilson Indexes
- Worldwide Political Science Abstracts

Conclusions and Recommendations

The past research on the VHS in Canada has produced 150 publications in total. It must be noted that the newspaper and magazine articles should be considered only as a sample of the available work. However, this caution has little to do with the academic research environment, as newspaper/magazine coverage is generally sporadic, and also has little to do with the organizational aspects of the VHS in general. Academic journals published 101 articles during the time frame covered by the literature scan (1971 through 2001), and such publications were condensed in the 1990s and 2000s. Another observation was the relatively late efforts to provide a theoretical background in understanding the organizational aspects of VHS in Canada, which are provided in manuscripts written by Febbraro et al.,[1] and Legowski and Albert[2] (both were written for the VHS project).

The major problem in terms of the publication gap seems to be the lack of a continued effort to create and sustain academic interest in the field. This could be done in a variety of ways.

First, a conference on VHS in Canada should be organized. As noted above, conferences prove to be topical and theme-oriented, and organizing a conference may prove to be a good way to raise some interest in academic circles. A ministry of health could call such a conference itself or invite a group of scholars from a number of universities to form a consortium that would define the parameters of the conference (theme/topic) and design the process for inviting submissions. As always, a conference may prove to be difficult to organize, requiring large sums of resources. In this case, stakeholders (federal and provincial departments and major voluntary organizations) may find a way to share costs. A topical conference may be effective on its own even as a one-shot event; however, periodical conferences have proven to be very effective in sustaining academic interest. In this case, a long-term commitment may be required for organizing annual events, each dealing with a particular aspect of the VHS.

Second, there seems to be a good number of dissertations/theses on the VHS in Canada. The authors of the most recent dissertations could be contacted to find out if there is any determination to publish such material. If so, a partial funding arrangement could be set up.

Third, one of the most important aspects of creating and sustaining academic interest has to do with academicians themselves. In this sense, a scholarship, funding arrangement on topical analysis of VHS in Canada should be announced. Most PhD students live in dire financial circumstances; there are many funding resources, such as the Millennium Foundation and Social Sciences and Humanities Research Council, but these resources require proposals in social science in general. A topical financial assistance scheme might draw attention from would-be scholars who are interested in doing research on the VHS. Such an arrangement would have a long-term research commitment on the part of the receiver of the funding, as the academic world works on the basis of specialization and compartmentalization.

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[1] Febbraro, A., M. Hall and M. Parmegiani. 1999. *Developing a typology of the voluntary health sector in Canada: Definition and classification issues*. Ottawa: Health Canada.

[2] Legowski, B. and T. Albert. 1999. *The Voluntary Health Sector in Canada: Outcomes and Measurement*. Health Canada.

Lastly, a research competition can be announced. In this case the participants may be asked to contribute to the understanding of the role of the VHS in the Canadian health system. Financial incentives may draw attention, albeit limited, from academic and professional circles that are interested in health policy in general.

3. An Inventory of Voluntary Organizations Providing Health and Health-related Services in Two Alberta Communities

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Introduction

Despite the recognition of the central role that voluntary organizations serve in promoting the health of Canadians, very little is known about the breadth and scope of services that voluntary organizations actually provide (Birdsell 2001).

The purpose of this research is to begin to develop an understanding of the contributions of voluntary organizations to the health of Canadians by undertaking an inventory of the types of organizations that exist, and the types of services they provide. This project begins on a small scale, by examining the voluntary organizations that provide health and health-related services in two communities in southern Alberta—one urban community (Lethbridge, population 70,000) and one rural community (Taber, population 7,000).

The Increasing Role for Volunteers and Voluntary Agencies

One of the foundational principles central to the health care system in Canada is that of universal access. Given the cultural and geographic diversity of Canada, it would appear to be a significant challenge to provide similar services and equitable access to services in all regions of the country. It is a further challenge to provide services in a cost-effective manner in regions that do not have a population base that will support infrastructure such as clinics, hospitals and drop-in centres, or personnel in the form of practitioners in a wide variety of disciplines.

In the province of Alberta, public consciousness has been raised regarding the issue of access to services as a result of the implementation of a regional system for health and health care delivery. The regional delivery system was proposed in Alberta in 1994 and implemented in 1995. Through the reorganization of formal health care delivery, more than 200 local hospital boards were replaced by 17 regional health authorities and two provincial boards. While each region is relatively autonomous, there are provincial guidelines for levels of care. Smaller centres provide basic levels of primary care, larger centres provide more advanced levels of care, and the large cities have highly specialized tertiary care facilities that provide advanced procedures such as open-heart surgery, advanced pediatric care, transplant services, and so forth.

The regionalization of health care delivery in Alberta creates two interesting dynamics regarding the role of volunteers and voluntary agencies. First, regionalization has been seen by many smaller rural communities as a move that has weakened local autonomy and decision making and has centralized many services to larger urban centres (Williams et al. 2001). This creates the potential for local volunteer agencies to play a more active role in providing or supplementing services that were previously provided locally through formal government programs and initiatives. Second, the move to regionalization has been utilized as a means to promote fiscal responsibility and rational business planning (Reay et al. 2000). The net result in many communities has been the reduction or elimination of services that were previously provided through the formal health care system but have been scaled back or discontinued for economic reasons.

An interesting research question then is the extent to which the types of services provided by volunteers and voluntary agencies differ between urban and rural centres. For example, are volunteers in rural settings more involved in the delivery of primary care services that were previously provided by professionals, while volunteers in urban settings are more involved in

support activities? Or are rural volunteers more involved in driving people to the larger centres to receive service? At the present time, there is very little research that provides any indication of the types of services and the types of organizations that exist.

For our purposes, we believe it is worthwhile to investigate and compare the types of voluntary organizations that exist in both urban and rural centres in order to gain an understanding of the similarities and differences. To do this, it is first necessary to develop a set of criteria or characteristics that can provide the basis for comparison and analysis.

Classification System for Voluntary Health Organizations

For several decades now, sociologists and organization theorists have wondered why there are so many different types of organizations, and they have developed various criteria, methods and techniques to categorize and analyze organizations (Pugh et al. 1968). Two approaches have generally been adopted: 1) taxonomies that seek to classify organizations based on the empirical establishment of observable characteristics, and 2) typologies that seek to classify organizations based on concepts or ideas developed by the researchers in generalized rather than specific terms (Miller & Friesen 1984; Slack & Hinings 1994).

Recently, efforts to synthesize the various approaches have resulted in the integration of various methods for classification and analysis. Greenwood and Hinings (1996) suggest that it is essential to explore both the structures of organizations and the systems and processes that connect the structural attributes. This suggests the need to examine and categorize not only the structural attributes such as size, division of labour, and so forth, but also process issues such as development of a mission, decision making, governance and ability to attract the necessary resources. These key characteristics can provide a basis for classification, analysis and comparison.

In searching the available literature related to voluntary health organizations, we found very little research designed to systematically classify voluntary health organizations. One exception is the work of Febbraro, Hall & Parmegiani (1999), which lays the groundwork for defining and classifying the voluntary health sector in Canada. An important contribution of this paper is the definition of what constitutes a voluntary organization. The authors suggest that the voluntary sector is most appropriately defined as including both non-profit and voluntary organizations. Following the work of Salamon and Anheier (1997), they identify five key defining characteristics of non-profit/voluntary organizations: 1) they are organized; 2) they are private; 3) they are self-governing; 4) they do not distribute profits; and 5) they are voluntary. Birdsell (2001) elaborates this criteria by explaining: "Conceptually then, [they are] organizations that are formally constituted to some degree, are separate from government, are equipped to control their own activities, do not distribute profits to their owners or directors, and involve some form of volunteer participation." (Birdsell 2001:2) For our purposes, this definition appears suitable and appropriate to define the types of voluntary organizations that provide health and health-related services.

Our analytical concern is at the organizational level and at the level of defining and analyzing the population of organizations in this sector. Using a generalized approach, we focussed on five fundamental aspects of voluntary health organizations to provide a basis for comparison. These were:

- the basis for organizing;
- the mission or purpose;
- the types of services provided and methods of providing them;
- internal processes and governance structure, and
- the methods of securing resources.

These five categories are based on the basic assumptions about organizations proposed in the widely accepted "open systems" model of organization (Scott 1987).

Research Methods

Research Sites

The city of Lethbridge has a population of about 70,000 people, and serves as the business hub of southern Alberta. The Chinook Health Region is headquartered in Lethbridge, and it serves a population of more than 150,000 people spread over several hundred square kilometres, including more than 20 small rural communities. The voluntary health sector plays an important role in Lethbridge and its surrounding communities. Within the city of Lethbridge there are more than 25 volunteer health organizations registered with an umbrella organization called Volunteer Lethbridge.

The town of Taber is a rural community located about 50 kilometres east of Lethbridge, and has approximately 7,000 residents. Taber has a local hospital that, prior to regionalization, was governed by a local board. The hospital and all other aspects of health in the community are now the responsibility of the Chinook Health Region headquartered in Lethbridge.

An interesting research question for us is how the services of voluntary organizations in these two communities (Lethbridge and Taber) are similar and different, and what relationship, if any, exists between voluntary agencies in the two communities.

In order to conduct such a comparative analysis, we developed an inventory of volunteer health sector organizations in an urban centre (Lethbridge) and an inventory of volunteer health organizations in a rural centre (Taber). We developed the classification system referred to above. We then developed, tested and administered a questionnaire with 18 questions, and tabulated our results.

Results

Through our investigation, 60 organizations in total were identified as the population of organizations. This included 46 organizations based in Lethbridge and 14 organizations based in Taber. We were successful in completing interviews with 40 of these organizations, which provided a response rate of about 67 percent. This included 9 out of 14 organizations in Taber, and 31 out of 46 organizations in Lethbridge. Our initial analysis involves analyzing the data from the two communities in aggregate form in order to establish basic patterns at the population level.

Basis for Organizing

Of the organizations surveyed, disease-based organizations were the most common, with 13 organizations reporting that this was their primary basis for organizing. Ten organizations identified themselves as primarily social welfare organizations, while four said they were primarily service organizations. None of the respondents identified religion, geographic region or culture as the primary basis for organizing. There were 13 respondents who indicated that the primary basis for organizing was something other than the six categories proposed.

The majority of organizations are organized around either a specific type of service delivery or some sort of general community service or support. Presumably, these organizations have emerged in response to a specific identified need or series of needs in the community that are not addressed by formal government programs or agencies. Many of the organizations identified the specific services and target clients groups in their mission statements.

The overarching emphasis on service to the public or targeted user groups was reflected in the fact that the majority of respondents indicated that number of clients served was their key evaluation criteria.

Table 3-1: Evaluation Criteria

Criteria	Number of Organizations	Percentage
Hours of volunteer service	11	27.5
Number of clients served	31	77.5
Staying within budget	20	50.0
Fundraising targets or objectives	13	32.5
Specifically established criteria	13	32.5
Population health statistics or indicators	5	12.5
Volunteer retention/turnover	8	20.0
Other	11	27.5

Type of Services and Service Delivery

These results reflect the nature of the organizations as identified through the questions about the basis for organizing. There is a much greater emphasis on health promotion and support than there is on primary health delivery and diagnosis of illness or conditions. Service related to enhancing quality of life was the most frequently cited service (77.5 percent), followed by education (75 percent) and health and wellness promotion (67.5 percent). The results show that the voluntary sector is playing a major role in providing services and support to help individuals obtain information and support necessary to sustain a healthy existence. The provision of these types of services would seem to reflect the societal trend towards greater emphasis on prevention, education and wellness.

Table 3-2: Services Provided by Voluntary Organizations

Service	Number of Organizations	Percentage
Diagnosis of illness or condition	1	2.5
Primary health care delivery	5	12.5
Support activities	16	40.0
Counselling and support	26	65.0
Health and wellness promotion	27	67.5
Prevention	22	55.0
Education	30	75.0
Advocacy	22	55.0
Research	7	17.5
Rehabilitation/adaptation	10	25.0
Palliative care	3	7.5
Community development	14	35.0
Quality of life	31	77.5
Referral services	25	62.5
Other	17	42.5

Another aspect of our research was to explore how the services identified above are actually delivered. These results indicated that the services the organizations provide are primarily demand-driven, with the most frequently cited method for service delivery being by request from the client, customer or user of the service (85 percent). The frequencies of the various responses are shown in Table 3-3 below.

Table 3-3: Types of Service Delivery Methods

Mode of Service Delivery	Number of Organizations	Percentage
Face to face	24	60.0
By request	34	85.0
Door to door	7	17.5
Lectures/seminars	23	57.5
Telephone inquiries	21	52.5
Hotline or distress line	5	12.5
Internet	15	37.5
Written materials: displays	29	72.5
Written materials: mail-outs	27	67.5
Media: TV/radio/newspaper	31	77.5
Other	13	32.5

A related area of interest was how the organizations established a relationship with clients, customers or service users. Again, an overwhelming number indicated that the relationship was typically initiated by the user, reiterating that these organizations are often driven by demand. The frequencies of responses to this question are shown in Table 3-4.

Table 3-4: Methods of Establishing Relationship With Client

Method	Number of Organizations	Percentage
Initiated by service provider	17	42.5
Initiated by service user	37	92.5
Provided to target groups	13	32.5
Provided on a broad basis	9	22.5
Targeted by demographic groupings	8	20.0
Targeted by geographic region	8	20.0
Other	7	17.5

Internal Processes and Governance

The scope of the organizations was evaluated in five categories: local, regional, provincial, national and international. The respondents had the option to provide more than one response, recognizing that many organizations may be a local chapter of a larger organization. The most frequent response to this question was regional (17), followed by local (11), national (10), provincial (4) and international (3).

In terms of legal status, there was only one organization that identified itself as for-profit. The other 39 organizations were non-profit, with a variety of legal arrangements such as registered societies, charitable foundations and so forth.

Decision making within the organizations was evaluated to establish how routine day-to-day decisions affecting local operations were typically reached. The board of directors was the most frequently cited decision-making body, followed by the local staff and/or executive director. Individual volunteers did not appear to be empowered to make decisions, nor did local presidents. Presumably, the decisions made by the boards were communicated clearly to provide guidelines and directions for the volunteers. This is an area where further, more in-depth research could provide additional insights.

The number of volunteers, paid staff and directors in the 40 organizations in Lethbridge and Taber is summarized in Table 3-5 below.

Table 3-5: Number of Paid Staff, Volunteers and Directors in 40 Voluntary Organizations

Statistic	Number of Paid Staff	Number of Volunteers	Number of Directors
Mean	10.11	242.48	8.13
Median	3.00	37.50	8.00
Mode	1.00	20.00	10.00
Standard deviation	25.51	701.55	3.74
Range	0–140	0–4000	0–17

Methods of Securing Resources

The data and discussion presented above relates to the services that voluntary organizations provide and how they provide them. An essential aspect of service delivery is having the human resources necessary to provide the services required. We explored this aspect of voluntary agencies by first seeking information about the types of contributions that volunteers make. Time and expertise were the most frequently cited responses.

Table 3-6: Contributions by Volunteers

Type of Contribution	Number of Organizations	Percentage
Specific services	20	50.0
Time	38	95.0
Money	27	32.5
Expertise	32	80.0
Products (t-shirts, coupons, etc.)	11	27.5
Cause-related marketing	9	22.5
Data management	15	37.5
Resource centre	11	27.5
Equipment	17	42.5
Attending fundraisers and events	19	47.5
Use of home or office	14	35.0
Canvassing	8	20.0
Other	5	12.5

Human resources are essential for voluntary organizations to operate, but so too are financial resources. The next area we looked at was the sources of funding that support the operation of the various voluntary organizations. The frequencies of responses are shown in Table 3-7 below.

The two most frequently cited responses were individual donations (72.5 percent) and fundraising (70 percent). In terms of the frequency values, it is interesting to note that regarding government support, provincial funding is the most commonly cited, followed by municipal and finally by federal.

Table 3-7: Funding Sources for Voluntary Organizations

Funding Source	Number of Organizations	Percentage
Donations from individuals	29	72.5
Endowments	8	20.0
Foundations	8	20.0
Municipal grants	12	30.0
Provincial grants	20	50.0
Federal grants	10	25.0
Corporate contributions	15	37.5
Contracts	9	22.5
In-kind donations	15	37.5
Fundraising	28	70.0
Other organizations	17	42.5
Other sources of funding	16	40.0

Affiliations and linkages was the third area examined under the heading of methods for securing resources. Only 18 of the 40 organizations indicated that they had formal (i.e. contractual) arrangements with other organizations. Those who did have formal arrangements typically had them with more that one other organization. Formal arrangements with government were indicated by 11 organizations. More organizations (18) indicated that they had formal arrangements with other voluntary organizations, while 12 indicated they had formal arrangements with institutions, and two indicated they had agreements with corporations.

Comparison of Lethbridge and Taber

When comparing the organizations in Lethbridge and Taber, one sees there are a number of parallel types of organizations in the two communities, as well as some unique aspects of each. However, overall, there was no unique or discernible pattern that would allow us to conclude that the two communities were fundamentally different in the types of organizations that exist and the types of services they provide. In both communities, the organizations appeared to be driven by the existence of specific needs that required attention. These include such basic necessities as food for those who do not have enough (food banks), seniors' associations, and transportation for persons with special needs (handi-bus). By focussing primarily on formal organizations, our current research did not delve into the acquisition of services from the consumers' point of view. Our suspicion is that many of the primary health services, and access to those services through driving and helping make appointments and so forth, are obtained through the informal networks of family and friends. Further research that focusses on the consumers' point of view could provide rich and meaningful insights into the distinctions and differences between urban and rural communities.

Summary and Implications

This research was designed to provide some preliminary insights into the scope and breadth of the voluntary sector as it relates to the provision of health and health-related services. While there are a plethora of classification systems and theoretical approaches for the analysis and comparison of for-profit organizations, there has been little research conducted on the voluntary sector, with the exception of the work done on voluntary sport organizations by Slack and Hinings and their associates.

In this research we have tried to theorize organizational characteristics that are observable and analyzable, and that will provide some meaningful basis for comparison. Our empirical approach has been primarily descriptive and included an open-ended component to allow us to develop emergent categories. Through our research we have established some criteria for comparison and have provided data based on two communities in southern Alberta. While our ultimate goal is to provide some comparative analysis between an urban setting and a rural setting, this initial analysis has looked at the data primarily in aggregate form to establish patterns and trends, and to test the appropriateness of our classification scheme.

Some of the traditional criteria for the comparison of organizations, such as formalization, centralization, and so forth, are less relevant for voluntary organizations that are typically informally structured and have diffused decision-making structures. Here we have focussed more on fundamental and foundational concepts such as basis for organizing, types of services and methods of service delivery. This approach has been useful in our preliminary descriptive analysis and suggests that future research in this view would be valuable. For example, in our initial search we did not find any organizations that were geographically based. Later in the study we did identify one tenants' association. While neither Lethbridge nor Taber is formally organized into neighbourhoods or communities, other cities are. Edmonton, for example, has a well-defined and established community league system that provides the organizational basis for many community programs and activities. It would be interesting to conduct systematic research in other centres to explore the extent to which the characteristics found in this study are unique to southern Alberta or generalizable to other regions of Canada.

Limitations of Research

There are many obvious limitations of research. First, while we set out to define and examine a population of organizations, we were not successful in gathering data from all 60 organizations identified. While it is our belief that the approximately 67 percent response rate is relatively representative of the entire population, there is no way to ensure this. Further, since organizations have varying legal status and mandates, there is no centralized information directory or database that could be referenced or consulted to ensure that we had identified all of the appropriate organizations.

Second, our analysis relies on a single source of information in each organization. While we made every attempt to seek out representatives who were knowledgeable about the organizations, each represents one point of view that may not be shared entirely by all members of the organizations. The vast majority of respondents (36 out of 40) were paid employees who represented a particular point of view.

Third, as noted above, the data we collected in this study was gathered from research sites in Lethbridge and Taber. While it is our ultimate aim to compare the voluntary organizations in the two communities, this initial paper was designed simply to test our assumptions about classification criteria, and to collect preliminary data. Consequently, the data from the two communities are presented primarily in aggregate form and do not provide the basis for extensive comparative analysis. That will be one of the subjects of our ongoing research and future publications.

Future Research

This paper has attempted to lay the groundwork for the development of an understanding of the types of organizations that provide health and health-related services in Canada by looking at two communities in southern Alberta. Basic criteria for comparing organizations were developed around basis for organizing, types of services, types of service delivery, internal processes and governance, and methods of securing resources. These categories provided insight into the types of organizations that exist and the types of services they provide. The research has suggested that the majority of organizations are driven by demand, or the need for services, in their respective communities.

This research has focussed on formal organizations that have some sort of structure and legal status. In the course of this research many people have observed the role that individuals and informal organizations also play. This is an entirely different aspect of the voluntary sector that is also worthy of research attention. The continuation of the work that has been initiated through this project, as well as the expansion of the research to include consideration of individuals and informal networks, are essential next steps to expand our knowledge and understanding of the increasing role of the voluntary sector in the provision of health and health-related services in Canada

As noted previously, this study was localized to southern Alberta, and may not be representative of other regions in Canada. Further research in other centres would be helpful and could provide the basis for comparative analysis. It may be beneficial to target other specific regions—for example, areas that have formalized community structures (such as Edmonton), and other provinces that do not have their formal health systems organized on a regional basis.

Bibliography

Birdsell, J. 2001. "Toward understanding the role and contributions of the voluntary health sector within the health system: An organizational focus." Ottawa: Health Canada.

Febbraro, A., M. Hall and M. Parmegiani. 1999. "Developing a typology of the voluntary health sector in Canada: Definition and classification issues." Ottawa: Health Canada.

Greenwood, R. and C. Hinings. 1988. "Organizational design types, tracks and the dynamics of strategic change." *Organization Studies* 9(3): 293–316.

Greenwood, R. and C. Hinings. 1996. "Understanding radical organizational change: Bringing together the old and the new institutionalism." *Academy of Management Review* 21(4): 1022–1054.

Hancock, T., R. Labonté and R. Edwards. 1999. "Indicators That Count. Measuring Population Health at the Community Level." *Canadian Journal of Public Health* 90(1): S22–S25.

Hart, K. 1987. "Volunteerism: the Breath of Life." *Canadian Business Review* 14(1): 8–12.

Kikulis, L., T. Slack and C. Hinings. 1992. "Institutionally specific design archetypes: A framework for understanding change in national sport organizations." *International Review for the Sociology of Sport* 27: 343–370.

Miller, D. and P. Friesen. 1984. *Organizations: A Quantum View*. Englewood Cliffs, N.J.: Prentice-Hall.

Miller, M., F. Farmer and L. Clarke. 1994. "Rural populations and their health." In J. E. Beaulieu and D. E. Berry (eds), *Rural Health Services a Management Perspective* 3–26. Michigan: AUPHA Press/ Health Administration Press.

Mintzberg, H. 1983. *The Structuring of Organizations*. Englewood Cliffs, N..J: Prentice-Hall.

O Connell, B. 1996. "A major transfer of government responsibility to voluntary organizations? Proceed with caution." *Public Administration Review* 56(3): 222–225.

Pfeffer, J. and G. Salancik. 1978. *The External Control of Organizations*. New York: Harper Row.

Pugh, D., et al. 1968. "Dimensions of organizational structures." *Administrative Science Quarterly* 13(1): 65–105.

Reay, T, et al. 2001. "Actor relationships in the dynamics of change: The changing Alberta health care system." Paper presented to the Administrative Sciences Association Annual Meeting, London, Ontario. June 2001.

Salamon, L. and H. Anheier. 1997. "The civil society sector." *Social Science and Modern Society* 34(2): 60–65.

Scott, R. 1987. *Organizations: Rational, Natural, and Open Systems*. Englewood Cliffs, N.J.: Prentice-Hall.

Scrivner, L. 1999. "Charities take their cues from business: Dwindling grants, competition put on pressure." *The Toronto Star*. November 30, first edition, p. B1.

Slack, T. and C. Hinings. 1987. "Planning and organizational change: a conceptual framework for the analysis of amateur sport organizations." *Canadian Journal of Sport Sciences* 12: 185–193.

Slack, T. and C. Hinings. 1994. "Institutional pressures and isomorphic change: An empirical test." *Organization Studies* 15(6): 803–827.

Slack, T. and L. Thibault. 1988. "Values and beliefs: their role in the structuring of national sport organizations." *Arena Review* 12: 140–155.

Smith, D. 1985. "Forward." In G. A. Tobin (ed.), *Social Planning and Human Service Delivery in the Voluntary Sector*. (pp xii). Westport, Connecticut: Greenwood Press.

Smith, S. and M. Sosin. 2001. "The varieties of faith-related agencies." *Public Administration Review* 61(6): 651–670.

United States Fire Administration. 1998. *Recruitment and retention in the volunteer fire service: Problems and solutions*. Emmitsburg, Maryland: Federal Emergency Management Agency, publication FA-185.

United States Fire Administration. 1995. *Emergency medical services recruitment and retention manual*. Emmitsburg, Maryland.: Federal Emergency Management Agency, publication FA-157.

Weber, M. 1947. *The Theory of Social and Economic Organization*. New York: Basic Books.

Williams, B., et al. 2001. "Organizational Transformation in Healthcare Delivery: The Case of the Taber Integrated Care Project." Paper presented to the Canadian Public Health Association Annual Conference, Saskatoon. October 2001.

4. Voluntary Organizations Within the Health Sector: Towards a Research Agenda

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Introduction

For the past 10 years, Canada has been undergoing fundamental reform in the health care sector. Often this involves structural change in which publicly funded health-related services are amalgamated into a regional governance structure. Services and activities of the voluntary health sector (VHS) have not been formally part of this reform, but are inevitably involved as the public system strives to achieve more effective and integrated delivery of services. It is important to understand the role and contribution of the VHS as health reform has become characterized by reduced levels of funding and the VHS has often become implicated as "part of the solution" (Gibelman and Kraft 1996; Steuerle and Hodginson 1998; Blackshaw 1995).

This paper reflects an exploratory effort to begin to outline a conceptual approach to understanding the role and contribution of organizations in the VHS to service delivery across the spectrum of health services, from health promotion and wellness through to palliative care. This conceptual approach has been informed by published literature, examination of annual reports of 20 national organizations in the VHS in Canada, and focussed reflection of seven researchers and non-profit leaders. The focus in this paper is on the nature and range of organizational relationships through which the VHS interacts and influences the formal health system. Voluntary organizations are seen as entities that are formally constituted for the purposes of contributing to improved health of Canadians in some way. The formal health system includes those aspects of our health system that are publicly funded: that is, the various levels of government and those organizations involved in delivering health-related programs and services. The paper sets out research directions that will assist in further efforts to describe and better understand the contribution of the VHS, and will thus inform future intersectoral initiatives.

Approach Taken

This project involved three components: a literature search, a content analysis of annual reports of 17 national health charities, and a focussed reflection of the information gleaned through those two processes by a group of experienced researchers and non-profit leaders. The expert group made suggestions with respect to a conceptual approach to increasing our knowledge of organizational interactions between the VHS and the formal health system. A summary of results from the review of annual reports is presented first, followed by findings from the literature, then by a discussion of conceptual frameworks, and finally suggestions for further research. A more complete description of methods and findings is available.[1]

Interaction as Portrayed in Annual Reports of Voluntary Health Organizations

Annual reports from the most recent year available from 17 Canadian health charities were reviewed. The purpose of the current analysis was to ascertain how these health charities described their interaction and relationships with organizations in the formal health system, which in this case is meant to include policy making bodies and those organizations that deliver health-related programs and services to Canadians.

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1 Contact J. Birdsell at **birdsell@on-management.com**.

Because annual reports are typically quite brief, and organizations try to provide high-level information on many topics, there is understandably limited detail within the annual reports with respect to interactions with other parts of the health system. Because of the brevity of information, selected "raw data" are presented so that the reader may critique the inferences made here. In the annual reports, there were six different types of relationships implied between VHS and formal health sector organizations. Several of these interactions represented direct influence on the formal health sector and some reflected indirect influence. These six, with examples of excerpts that typify this category, are given below.

Typical relationships that reflect direct interaction

Direct funding. For example, "The Foundation has once again provided partial salary support for 18 registered nurses attached to selected neurologists or VON [Victorian Order of Nurses] clinics across Canada as part of its Clinical Assistance and Outreach program." (Muscular Dystrophy Association of Canada)

Contracting by voluntary organization. For example, "In September 1999, CMHA [Canadian Mental Health Association] was designated as the Mental Health Affiliate partner for the Canadian Health Network, a national, bilingual, Internet-based health information service funded by and in partnership with Health Canada...."

Organizational representation. For example, "Society staff worked on government task forces and voluntary agencies to address common concerns and recognize the importance of the voluntary sector." (Alzheimer Society)

Collaboration. For example, "The Canadian Cancer Society and its research partner, the National Cancer Institute of Canada, are very proud of the role they have played in partnering with Health Canada and the Canadian Association of Provincial Cancer Agencies to help develop the Canadian Strategy for Cancer Control. Dorothy [Dorothy Lamont, former Chief Executive Officer] developed a relationship with the federal government that has given cancer control the ear of the government. A consortium of Health Canada, the Canadian Association of Provincial Cancer Agencies, the [Canadian Cancer Society] and [National Cancer Institute of Canada]—brought together by Dorothy—is fine tuning the first Canadian Strategy for Cancer Control."

Examples where there is evidence of indirect influence

Support of third-party activity. For example, "In 2000, the CCFF's [Canadian Cystic Fibrosis Foundation] site visit program sponsored reviews of five clinics to help ensure standardized, high quality clinical care across Canada. Site visits conducted by members of the Clinical subcommittee and other Canadian clinical leaders allow the clinic team and reviewers opportunities to discuss national standards of care, to promote and exchange ideas on medical, administrative and social issues, and to offer third-party support."

Arm's-length influence. For example, "In addition to advocating for the rights of people with diabetes, we have increasingly dedicated resources to government relations and public policy to ensure that the disease is a national priority. We actively advocated for a diabetes institute named by the federal government's Canadian Institutes of Health Research." (Canadian Diabetes Association)

Generally speaking, there is very little evidence arising from the national level annual reports of health voluntary organizations that reflects interorganizational relationships with service delivery organizations at the community level, other than perhaps through the direct funding of clinical personnel in specialized areas. As the programs and activities reported in these annual reports are countrywide in nature, one might assume that they are in place because a general sense of need has arisen from many communities across the country. It is important to remember that the annual reports examined in this report were from the national level of organizations. In most cases, there are other levels as well (community, regional or provincial). Therefore, the nature of the information included in these annual reports is fairly general. One should not assume that these reports reflect the total interactions among the voluntary health organization in question and various components of the health system. It was a convenience sample, and observations made here serve only as a beginning exploration of the nature and range of relationships and interactions between organizations in the voluntary sector and the formal health sector.

Interaction as Portrayed in the Literature

This work represents an exploratory effort to identify relevant literature with a view to helping to build a conceptual framework that would help one to view, and eventually to understand, the role and contributions of the VHS to health outcomes in Canada. The literature accessed for the purposes of this review includes articles related to interorganizational relationships, the role of the voluntary sector in society, interactions between the voluntary sector and government and between voluntary organizations and rural health and primary health care. Brief summaries on each of those areas follow.

Interorganizational relationships. Although there is little published literature that specifically addresses interactions and relationships between organizations in the VHS and formal health sector, there is research relating to collaborations at the community level involving one or more voluntary organizations (e.g. mental health: Provan & Sebastian 1998; Canadian Heart Health Initiative: Stachenko 1996). This research has largely focussed on either structural aspects of these interorganizational relationships or on process issues. There is no explicit attention paid to the specific role, contribution and actions of voluntary organizations as compared to others. It is not clear that this differentiation is necessary either, but this conclusion should not be assumed in the absence of evidence.

Role of the voluntary sector in society. The purpose of this literature review was to glean a sense of the range and nature of interactions between organizations in the VHS and the rest of the health system. This assumes that voluntary organizations can be legitimately considered as part of the health system, perhaps an assumption that should not go unquestioned. At some point, it will be important not to consider the implications of framing voluntary health organizations within the health system without carefully considering the societal and historical context within which voluntary organizations are traditionally viewed. If one were simply to focus on voluntary health organizations as one more mechanism through which to address some of the myriad of needs that exist within the formal health system, it would ignore some of the broader issues involved in the maintenance of a civil society and the role that voluntarism plays therein. For example, some assert that the voluntary sector plays a critical role of providing a vehicle for expression of altruism and citizen involvement (Laws 1997; Dobrof 1998). Some feel that the drive to contribute and do something worthwhile is a basic human need (Dobrof 1998).

This relates more to a supply side role, as compared to a demand side role. It does suggest, however, that one cannot examine only the output side of a system that involves volunteers who are meeting some of their own needs (which may be unrelated to the mission of the voluntary organization) through a particular voluntary organization.

Interactions between voluntary sector and formal health system. This includes interactions with the government and with agencies that deliver health services. Most of the literature that specifically addressed relations between voluntary or non-profit organizations and other entities also discussed VHS-government relations (e.g. Birdsell et al. 1992; Boris and Steuerle 1999). Despite the differences in policy environments in different countries and the particular mix of services and financing arrangements for health care, at a high level it is fair to describe general roles of the non-profit sector in relation to government as being supplementary, complementary or adversarial (Young 1999). In a study of two industries, Kapur and Weisbrod (2000) found considerably different behaviour between government and non-profit agencies providing similar services. They interpreted their results as reflecting the position that governments are suppliers of last resort, and will not turn anyone away, whereas non-profits, as they are not philosophically or legally obligated to serve all, can limit access to improve quality.

Interactions with organizations other than government in the formal health sector can be described as direct service provision, playing a mediating or linking role and democratizing health information. The evidence of effectiveness of the VHS in interactions regarding clinical care with the formal health sector is mixed (Robbins et al. 1996; Addington-Hall et al. 1992). In addition to clinical care, service delivery in collaboration with the formal health sector includes health education, transportation, mental health and community health centres. The linking and mediating role is a large one for the voluntary sector, as organizations are often comprised of representatives of groups in society with a particular interest, and therefore they provide a focal point through which other organizations can interact for purposes of collaboration on shared issues, or for seeking input from a particular constituency.

Towards a Conceptual Overview of the Relationship Between the Voluntary Health Sector and the Formal Health System

Conceptual frameworks serve a useful purpose in shaping and interpreting research in a particular field. Clearly articulated conceptual frameworks enable the interpretation of existing research that may be available, but that needs to be interpreted within a certain frame. Even if the context within which one is interested in interpreting the research is not identical to the one presented in the research, if one has a "frame" through which to view the research it may be more fruitful (Robinson 2001). It is too early to propose a theory of organizational interactions involving the voluntary sector. However, it is useful to identify some dimensions for examination in an overall consideration of organizational relationships in the voluntary sector. Dimensions that need to be examined, or at least clarified, in ongoing research include those listed below. The identification of these dimensions arose from a workshop during which participants considered results of the literature identified and also the annual reports of health charities.

Extent of formal organization of volunteer efforts. Volunteer efforts occur within a range of contexts, from totally without any formal organization to highly formalized

organizations. The focus in this paper is explicitly organizational, in contrast to much research that collects information about the role and contributions of individuals to society.

Power relations between and among organizations involved in interactions. When trying to understand the nature of interaction between organizations and the impact of those interactions, the relative power of the two organizations must be taken into account. This might include dimensions such as the size of the organizations, resources available (financial and human), the decision-making authority of the representatives involved, the level of autonomy of the organizational entities, and the level of prestige accorded the organization by society at large.

Clear articulation of the differentiation between public, private and voluntary sectors. It is intuitively appealing to split the world into three separate and distinct components, but this is not easily possible in a way that helps to guide research. The focus in the current work has been on interaction between organizations in the voluntary sector and those in the formal health sector (including both government and health service delivery organizations). There are organizations in the health system that are private, but are publicly funded. Physicians in private practice (either singly or in groups) are perhaps the most obvious ones. Even in this case, there could be debate about whether these are classic private sector organizations, as most revenue accruing to physicians comes from public sources. Are physician practices best viewed as private sector organizations or as publicly funded services managed through a third party funded by government? In any case, there are private organizations involved in delivering health-related services as well, so it may not be adequate to focus attention only on the voluntary sector and publicly funded organizations. In a complete view of the health system, organizations within the private sector also play a role, whether that is in providing goods or services (massage therapy clinics, health food products, counselling services). Increasingly, as well, the distinctions between the sectors are blurring as charitable organizations adopt strategies more commonly associated with private sector businesses, and businesses are increasingly concerned with more socially oriented dimensions such as worker health and other dimensions important to society at large (e.g. environmental issues). At the very least, it is important to specify the assumptions when labelling organizations coming from one sector or another.

The nature of the organization. Certain key characteristics of an organization make that organization more or less able to engage and be effective in different types of activities. These characteristics include such things as the organizational structure, number and type of staff (paid or unpaid, level and type of expertise), and governance (member organization, corporate structure, cooperative). The origins of the organization may also be important. Many voluntary organizations are created as a result of an identified need by stakeholders (hospitals, physicians groups) within the health system; others truly arise from community-based concerns and are "grassroots" in origin.

The focus of intended impact. The health system is complex, and there are varying levels and locations of intended impact. The level varies from local community to provincial and national; the focus of attention might be health-related activities in the local community, or in primary, secondary or tertiary services, or at the policy or societal levels.

Underlying assumptions and values. This dimension can include a wide range of often unspoken values, attitudes and assumptions affecting interactions between sectors. It may include, for example, mistrust or dislike of the organization in the other sector, or a general mistrust of all organizations who represent the "system" or who represent "do-gooder" volunteer

organizations, or an underlying belief that voluntary health organizations should "act like businesses."

Health dimensions of interest and their definitions. The dimension and definitions of health-related concepts that are of concern have an impact on the scope of interactions of interest. For example, the concern could be with physical, mental, social or spiritual aspects, or indeed may be related to underlying determinants of health (which would allow conceptually a much broader range of activities to be included within a health discussion).

Task or problem attributes. The specific nature of the issue being addressed in interactions between the VHS and formal health sector needs to be considered when trying to understand the mechanisms of influence. For example, interorganizational interactions between voluntary health organizations interested in reducing the impact of tobacco use on the health of Canadians are multidirectional, longitudinal and, it seems, never ending. On the other hand, if the issue at hand is to ensure public coverage of some medical device that makes the life of an affected person much easier, then the nature of interaction is very focussed, and there is a clear end point. These two situations would lead to much different interaction between the VHS and the formal health sector.

The context for the interaction. This is a huge category of dimensions that no doubt will eventually need to be subdivided. Characteristics of the context or situation that may theoretically impact the nature of interorganizational interactions include, but are not limited to the prevailing government philosophy about voluntarism and contracting out, the characteristics of health reform in a region, the geographic setting (urban, rural), the ethnocultural community of interest, the population profile (number and nature) of voluntary organizations within a particular region, and public opinions with respect to the VHS and the formal health sector, or the degree and nature of community need.

Outputs and outcomes. There has been precious little explicit attention paid in the literature to date on what the "hoped for" outcomes are with respect to interactions between the VHS and the formal health sector. One can imagine that they include such things as ultimately changing the nature of services provided by the public system (which may be why a small organization would provide direct funding for staff to a health delivery organization with much larger resources), changing public policy, or improving health outcomes in a specific subset of patients. We know this to be the case when program evaluations are done that focus only on the activities of a voluntary health organization. However, we do not know the intended outcomes of interactions between the sectors. It is not unreasonable to think the outcomes are similar, but the means of achieving them are different, perhaps depending on context.

Implications

Given that there is so little emphasis on the organizational relationships between the VHS and the formal health sector in the literature and in publications arising from the sector itself, one must ask why this is important to consider? There are several reasons why it may be helpful to understand more about the interactions and relationships between organizations in the VHS and in the formal health sector. We live in an organizational world, and it seems imperative to understand the impact of organizations within the health care system. Some policy questions that

could potentially be at least partially answered by having improved knowledge of organizational actions and impacts of the VHS include the following.

- What might the potential impact be of government grants to voluntary health organizations?
- What contributions do voluntary health organizations make to health in Canada?
- What models of interaction translate into improved health or improvements in health services delivery?
- Can voluntary health organizations "pick up the slack" (for example, in transition from institutional care for mentally ill to the community)? Under what conditions can they do so?
- In which situations is contracting with a voluntary health organization to provide services advantageous?
- In which situations can a voluntary health organization play the most effective role in linking or mediating between various components of the health care system?

The present study is one piece of a mosaic that may eventually lay the foundation for work that directly informs the policy questions identified above.

Recommendations for Further Research

1. Observational and descriptive studies on the nature and extent of organizational interactions between the VHS and the formal health sector and the impact of those interactions. This may include, but not be limited to, interactions that are collaborative in nature. Ideally these would be done within a clearly defined context such as specific size of community, within a specific health focus or defined according to one or more of the dimensions identified in the earlier discussion related to a conceptual framework. Both quantitative and qualitative studies are needed.
2. A systematic review of factors contributing to successful interoganizational relationships involving organizations in the voluntary sector (including unpublished literature). Most of the literature does not focus on the type of organizations that are collaborating. Much of the research may be relevant to voluntary organizations, but it is not clear to what degree that is the case, or if in fact there is any reason to view voluntary organizations differently with respect to collaboration processes. Given the huge range of the size, intent and governance of voluntary organizations, for example, the degree of relevance to the voluntary sector is not clear.
3. Population level studies
    a) Comparison of the relative nature and extent of contributions by volunteers engaged within the formal health sector (such as in hospitals and in those organizations that are formally constituted within the voluntary sector). The focus in this paper has been on organizational influence and interaction. This is in contrast to much of the research, which has focussed on volunteering, with individuals as the point of departure. There are many dimensions about which knowledge gleaned about the activities and impact of volunteers in any particular health care setting makes no difference if the volunteers are working within the umbrella of a public organization or within a voluntary organization.

However, the focus of interest here is on organizational interaction and influence. Since there is very little work done in this area, teasing out these interrelationships will require careful thought.

b) Research to describe, from the system level, the profile (number and nature) of voluntary organizations present in a defined community. The impact and role of an organization in a field that has one voluntary health organization focussing on a particular health issue may be quite different from the impact within a field containing 10 organizations focussing on one health issue.

4. Examination of the impact of voluntary organizations in different contexts in order to identify the confluence of dimensions in which voluntary organizations have a unique comparative advantage for effective action.

Closing Comments

The development of a body of knowledge relating to the role and impact of voluntary health organizations on the health of Canadians is in the early stages. While there are individual studies that inform various aspects of the actions of voluntary health organizations, there is insufficient work to enable a general understanding. In the short run, it is important to outline a conceptual framework within which to view these relationships so that research contributes to our understanding in an incremental way. This paper has made beginning steps in that regard. While this body of knowledge develops, it is helpful to view the field through several lenses: organizational theory, political science, economics, geography and sociology. Increasing our understanding of organizational impact will provide some return on investment to both voluntary health organizations trying to make a difference, and also to funders, including the government, making decisions about resource allocation on a regular basis.

Bibliography

Addington-Hall, J. M., et al. 1992. "Randomized controlled trial of effects of coordinating care for terminally ill cancer patients." *British Medical Journal* 305: 1317–1322.

Birdsell, J. M., M. E. Schwann and R. Tremblay. 1992. "Reaching native groups in the Northwest Territories: A report of a joint project between government and a voluntary agency." *Canadian Journal of Public Health* Sept.–Oct.: 335–336.

Blackshaw, D. 1995. "Power to the people (with care)." *Nursing Management* 1(10): 18–19.

Boris, E. T. and E. Steuerle. 1999. *Nonprofits and Government: Collaboration and Conflict.* Washington, D.C.: The Urban Institute Press.

Dobrof, R. 1998. "Philanthropy and government: partners in community caring." *Dignity and Old Age* 29(2–3): 147–154.

Gibelman, M. and S. Kraft. 1996. "Advocacy as a core agency program: Planning considerations for voluntary human service agencies." *Administration in Social Work* 20(4): 43–59.

Kapur, K. and B. A. Weisbrod. 2000. "The roles of government and nonprofit suppliers in mixed industries." *Public Finance Review* 28(4): 275–308.

Laws, G. 1997. "Voluntary organizations and advocacy: The case of housing for older Americans." *Nonprofit and Voluntary Sector Quarterly* 26(3): 307–342.

Provan, K. G. and J. G. Sebastian. 1998. "Networks within networks: Service link overlap, organizational cliques, and network effectiveness." *Academy of Management Journal* 41(4): 453–463.

Robbins M. A., P. Jackson and A. Prentice. 1996. "Statutory and voluntary sector palliative care in the community setting: National Health Service professionals' perceptions of the interface." *European Journal of Cancer Care* 5(2): 96–102.

Robinson, J. C. 2001. "Organizational economics and health care markets." *Health Services Research* 36(1): 177–189.

Stachenko, S. 1996. "The Canadian Heart Health Initiative: a countrywide cardiovascular disease prevention strategy." *Journal Human Hypertension* 10(Supp. 1): S5–S8.

Steuerle, C. E. and V. A. Hodginson. 1998. "Meeting social needs: Comparing the resources of the independent sector and government." In Elizabeth T. Boris and C. Eugene Steuerle (eds.) *Nonprofits and Government: Collaboration and Conflict,* pp 71–98. Washington, D.C.: The Urban Institute Press.

Young, D. 1999. "Complementary, supplementary or adversarial? A theoretical and historical examination of non-profit government relations in the United States." In Elizabeth T. Boris and C. Eugene Steurle (eds.), *Nonprofits and government. Collaboration and conflict,* pp 31–67. Washington, D.C.: The Urban Institute Press.

5. The Voluntary Health Sector:

Integrators Across Health Domains

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Introduction

What Are We Talking About?

Several public policy interests of the Government of Canada intersect in the topic of the "voluntary health sector." For example, consideration of changes in the publicly funded health system is taking place at the same time as the federal government is directing policy attention to improving relationships with the voluntary sector. This examination of voluntary sector "community health centres" illustrates the concept of "community" as a key link between these two policy themes, and examines community health centres as integrators across determinants of health, communities and sectors of society.

The Primary Health Care Reform Policy Direction

After 35 years of operation, the well-being of Canada's publicly funded health care system is being questioned. Is the health of Canadians improving? Are taxpayers willing to pay what seem to be the inexorable costs of an aging population? What incentives will encourage change from fee-for-service billing methods to cost-effective, cost-contained payment systems? How can promotion, prevention and protection be strengthened? How can continuity of care and integration of services be improved?

The current focus of reform is on primary health care, which the World Health Organization distinguishes from primary medical care, or first contact medical or health care. It is, rather, intended "to reach everybody, particularly those in greatest need; to reach to the home and family level, and not be limited to health facilities; to involve a continuing relationship with persons and families."[1]

What role can voluntary health organizations play in reform of the health system? This paper examines the activities of "community health centres" in Eastern Ontario within the framework of the determinants of health. It also explores how their extensive use of partnerships and their focus on building community capacity holds great promise for primary care reform.

Community Health Centres: A Voluntary Sector Model of Primary Health Care

Against a backdrop of public policy interest, the role of one mechanism for delivery of primary health care through a voluntary sector participant in Canada's health care system may hold particular promise for health care reform. Voluntary sector community health centres (CHCs) provide a model for meeting a wide range of primary health care needs of Canadians. As community-based organizations, CHCs carry out their primary health care functions through multidisciplinary staff teams and intersectoral partnerships across communities. What strengths does the voluntary sector CHC model bring to primary health care? What can we learn from this model of voluntary sector engagement in health?

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[1] World Health Organization, 1988, *From Alma-Ata to the Year 2000: Reflections at the Midpoint*, pp. 15–16. Geneva: World Health Organization.

The Community Health Centre Model: Grounded in the Voluntary Sector

The foundation of the community health centre is its community. CHCs originate in people who come together around health issues and needs, and are able to organize their neighbours. These grassroots volunteer efforts carry over into the governance of an operating CHC, which is a non-profit organization with a board of community volunteers. Through formal bylaws, annual meetings, and regular client and community consultation processes, the CHC maintains its accountability to its roots and reflects community needs in its programs and services.

This connection to community is expressed in vision and mission statements that set out a broad and deep definition of health, a definition that extends beyond the individual to the whole community, beyond the absence of illness to the promotion of wellness for individuals, families and the community at large. This vision recognizes the CHC as a vehicle for improving health, and leads to a focus on partnerships—with individuals on their own health concerns, and with community organizations and other agencies on broader social issues. It signals a fundamental role of the community health centre to build the capacity of individuals and communities to take action to improve their own health conditions.

Each CHC carries out its mission through a service delivery philosophy that clearly reflects its community roots. Its services are client-centred, respecting a person's understanding of their own needs and involving them in decisions about how to improve their health and quality of life. The approach to health issues is holistic—seeing the whole community and the individual's place in it. Multidisciplinary teams within the CHC work together to respond to the array of needs and situations presented. The holistic view of health combined with the recognition that the centre must work with people individually and collectively to address concerns results in a basic CHC strategy to collaborate and cooperate with a variety of other actors to achieve healthy outcomes. To promote wellness, the CHC reaches out to people where they are, helps them develop the capacity to act on their health needs, and connects them to other partners that share common cause. This is the CHC as an integrator, a catalyst, a bridge between various community interests and between the traditional health system and the community itself.

The vision and mission of a CHC and its service delivery philosophy are the statements of principle that guide its development and operation. These statements clearly define the CHC in relation to its accountability to its community and to its broad focus on health and community empowerment. The name "community health centre" is, therefore, not simply a nice choice of words. It is in effect a brand name, denoting a very specific approach to individual and community health. The brand comes with a guarantee of sorts, because the CHC's foundation in the community has become formalized, or institutionalized if you will, through two significant processes.

The first is an accreditation process titled Building Healthy Communities, which is carried out by an independent organization and teams of peer reviewers on a three-year cycle. There are five building blocks for accreditation: governance, management, administration, community capacity and programs and services.

The second process that institutionalizes and "guarantees" the CHC brand is the framework that guides the evaluation of the CHC's program effectiveness. This framework was recently developed by CHCs through their provincial association, and has been endorsed by the primary funder, the Ontario Ministry of Health and Long Term Care. The indicators by which a

CHC is assessed fall under five categories: accessibility, holistic and client-centred service, individual and community capacity building, comprehensive programs and services delivered through multidisciplinary teams, and focus on wellness and prevention. Few if any of these evaluation categories could be demonstrated by a health agency that is not grounded in the community and its voluntary networks.

As a result, for a health agency or organization to call itself a community health centre in Ontario, it has to be a non-profit voluntary agency with accountability to its community, a demonstrated commitment to health promotion and a particular community development focus for its service delivery.

The network of community health centres in Eastern Ontario provides ample illustration of how these principles and requirements are carried out in the real world. Whether urban, suburban or rural, whether serving a geographic community or a particular population (French-speaking residents or Aboriginal people), all centres use partnerships throughout their program spectrum: health promotion, early intervention, chronic disease management, social action and community capacity building. The partners are many and varied, and become involved because of their particular interests and resources and because of a common focus on a target group or health concern. The partners include hospitals, public health units, other CHCs, voluntary health associations (the Canadian Diabetes Association or the Arthritis Society, for example), schools, social agencies, churches and faith organizations, all levels of government, housing agencies, universities, community associations, service clubs, businesses and the police.

Frequently, a single program involves several partners, with the CHC as the connector. Different groups and agencies can contribute various things—for example, space, program supplies, funds, materials, advice and expertise, volunteer and/or staff support. CHC roles can also differ in the partnership depending upon what is being asked of them and what they are best able to offer. These roles can include any or all of the following: management and coordination, advice and expertise, space, materials and supplies, training and supervision, staff and volunteer support and, in some cases, funds. The network of support for a given initiative reflects what each partner can best contribute.

A survey of the Eastern Ontario CHCs shows that this strategy of working in partnership extends to the full spectrum of possible target groups, whether defined by age, gender, income level, cultural group or health issue. The specific focus depends on the community served by the CHC and the nature of the initiative. So, for example, a large downtown CHC may have strong partnerships targeted at services to the gay/lesbian/bisexual/transgender community or homeless men and women, while a rural community may have focussed partnerships dealing with youth at risk or isolated seniors.

Community Health Centres: Integration in Action[2]

These six examples or case studies demonstrate the characteristics of CHCs that make them an effective model for positive reform of the primary health care system.

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[2] All information about community health centres in Eastern Ontario results from responses to a questionnaire and interviews by Marguarite Keeley in September 2001. The authors thank the staff and board members who responded to this request.

Building Community Capacity: Carlington Health and Community Services

Through strategic planning consultations, the CHC board identified many service needs for the families in a low-income rental housing neighbourhood. The six market-rent buildings housed about 500 families. Tenant turnover was very high and the environment was unsafe for residents. While it was in the CHC catchment area, this neighbourhood was just far enough from the centre to limit accessibility to services offered there. The murder of a child in the neighbourhood prompted a local Rotary Club to go to the CHC offering its help if the CHC staff would show them what to do.

The CHC met with residents who identified the need for programs that would address community safety concerns, provide stimulation for children and youth, and support families in difficulty. Together with the CHC and the Rotary Club, the community undertook to bring in a range of health and social services, and to involve residents in making their neighbourhood safe. The CHC set up a satellite medical clinic, provided the services of a community developer to work with residents on their concerns, and acted as the broker to bring in services from other agencies.

Today, this neighbourhood has core medical services, infant stimulation and children's programs, a "baby cupboard" with clothes and toys, a computer club and a literacy program. The residents started a Neighbourhood Watch program and have seen the numbers of calls to the police go down substantially. They have built a park and set up a Good Food Box Club (that offers fresh vegetables and fruit at low cost because of direct purchase from a supplier). Many of these programs are supported by volunteers from the Rotary Club and from the community itself. The result is a community where tenant turnover has been reduced, residents are active in helping offer community services, and the neighbourhood is a safer place.

This satellite program involves many partners: the CHC as the integrator, broker and provider of medical services, the Rotary Club as a source of funds, in-kind resources and volunteer program leaders, churches offering volunteers, funds and in-kind resources, the local food bank, a youth services agency, the Boys and Girls Club, and the landlord, who provided space for programs.

Health Education and Chronic Disease Management: Centretown Community Health Centre

Recognizing that type 2 diabetes is a growing health problem, the Ontario Ministry of Health decided to invest in new approaches to provide diabetes services at the community level. With the support of the Ottawa Coalition of Community Health and Resource Centres, the CHC took the lead in establishing the Ottawa-Carleton Diabetes Services Network. This network brought together all the key players offering diabetes services—four local hospitals, the public health department, the Canadian Diabetes Association, and the Community Care Access Centre—with the purpose of identifying service gaps, planning coordinated interventions and ensuring effective use of resources. Through coordinated planning, the network aims to ensure that people receive the level of service they need from the appropriate service provider. At the community level, primary care education and support is managed and operated by CCHC.

The program itself comprises group education sessions with follow-up and individual support. The key staff are a nurse educator and a dietician who deliver the program in a variety of locations throughout the greater Ottawa area. In 2000–2001, more than 50 sessions were

offered to more than 600 people in four languages besides English and French, and assistance was provided to an Aboriginal health access centre. The team also trains trainers in other centres, and has developed a trainers' guide that has been sold across Canada, along with a modified Canada Food Guide for people with type 2 diabetes. All client materials are available in several languages.

People can register themselves in the program or be referred by one of the partner agencies. Some clients are now being referred by private physicians after outreach by the team to let physicians know about the service. The program is a great success and is being used nationally as a model. Clients have reported significant improvements in their health, and are making sure they keep up the practices learned. Hospital specialists are reporting fewer people using their services when they could more appropriately be served by the CHC program.

The CHC played the lead role in strategic planning, management and program coordination. By developing guides and materials, and by training other service providers, the team has disseminated the model so other communities can also benefit from their experience.

Nutrition Services in a Rural Community: Merrickville and District CHC

The Merrickville and District CHC serves a large rural area southwest of Ottawa. Staff at one of the rural schools noticed that many of their students were arriving after a long bus ride without having eaten any breakfast. They realized this created learning problems for their students but were not sure how to raise the matter with parents in a positive way. The school approached the CHC because its staff complement includes a nutritionist. With her help, the Morning Snack Program was launched. The program now provides nutritious snacks to all students (about 200 from grades 1 to 8) when they arrive at school. All parents are asked to contribute $4 a month, but students can participate whether or not their parents have contributed.

The CHC role was key. The nutritionist offered advice about nutritious snacks and provided program coordination. The CHC provided organizational support and encouragement so the parents' council could take over program operation. It also acted as a catalyst to bring together parts of the community that had not worked together before. Local businesses provide cash donations and volunteers; the school offers space and in-kind resources; the parents' council provides volunteers, raises funds and publishes a newsletter.

The community has rallied around this program, and has also developed awareness about the importance of a healthy breakfast for children to be able to learn. It is a simple program with significant health impact.

Supporting High-Risk Youth in Rural Ontario: North Lanark CHC

Many young people in this rural community were dropping out of school and getting in trouble because of having nothing to do. Other students were facing learning disabilities, poverty or social and geographic isolation. The CHC Community Developer brought together representatives from the local schools, a child and youth mental health agency, and an existing school-based nutrition program. They secured project funds from several foundations as well as the National Child Benefit. A multifaceted program was launched, comprising recreation programs, a drop-in with a nurse practitioner and social worker on site, psychosocial support groups in the schools, transition programs for students moving into high school, and an extended school snack program. Young people were also encouraged to take leadership in the community,

and developed a skateboard park in the village. Between 50 and 80 young people take part in these programs on an annual basis. Youth in crisis are now more comfortable seeking help at the CHC and the schools are beginning to take over some aspects of the program for the longer term.

The CHC was the driving force behind the program and the only agency with the community development resources to do the organizational work that made the program a success.

Building Employment Skills Among Youth at Risk: Somerset West CHC

Somerset West CHC is in an older urban neighbourhood of Ottawa. The CHC had been concerned about the number of high-risk youth who were unemployed and facing barriers to education and employment services. When the federal government withdrew its mandate for training programs, access to youth employment services threatened to disappear altogether. The CHC decided to capitalize on the presence of a vibrant high tech industry in the city, and to bring key partners together to deal with the problem.

The CHC convened representatives of the municipal, provincial and federal governments, the Youth Services Bureau (an agency supporting at risk youth), the school boards, the local university and community college, and 32 medium and small high tech companies. CHC staff convinced the partners to participate in a Youth Employment Apprenticeship Program, which combines technology and computer skills training with life skills training over 14 weeks, followed by 14 weeks of work placement. Funds were secured from the city government and the Ministry of Colleges and Universities, while local partners contributed their help in curriculum development, educational upgrading and work placements. After three years, 99 youth have gone through the program and 85 percent are either employed or pursuing higher education. Follow-up testing has shown that their health and self-esteem have increased, their housing has stabilized and they have reduced their use of alcohol and drugs.

The program addresses income and social status, employment, social support networks, physical and social environments, personal health practices and coping skills, education and health services. The CHC manages the program, providing staff and in-kind support as well as follow-up evaluation with the program graduates.

Community Economic Development: Centretown Laundry Co-op and Centretown CHC

Four years ago in Ottawa, poverty groups held Peoples' Hearings to speak about the issues confronting people with low income in the city. The hearings coincided with substantial cuts to welfare rates and services by the provincial government. Two Centretown churches decided to respond by working in partnership with Centretown CHC and low-income and street-cultured community residents to create a laundry co-op. This affordable self-service laundry opened in a local site housing a number of community-based services. People join the co-op by paying the $1.00 membership fee, and then can do their laundry for a fraction of the cost at a commercial laundromat. The churches provide leadership, have legal responsibility for the project, and raise funds while a representative from the CHC sits on the governing body, provides office space as well as supervision and administrative support for a coordinator and part-time outreach workers. The CHC also brings its strong linkages with other community agencies to help support the operation of the program and its members. The service has become a meeting ground and confidence builder for its members, who participate in all aspects of the

operation and are becoming more involved in governance. Members are now exploring ways to generate income for themselves by doing laundry for local businesses.

This practical project addresses many of the determinants of health: income and social status, social support networks, employment and working conditions, social environments, personal health practices and coping skills, and culture.

These case studies show the extent to which connection to community drives CHC operations. CHCs build and participate in coalitions, networks and partnerships—sometimes with like-minded agencies and sometimes with otherwise disparate community elements. The focus on the determinants of health and the modus operandi of the CHC instinctively reaches out and draws in partners; CHC staff teams actively look for ways to bring people and organizations together to work on community health issues. They create openings for the voices and strengths of community members to develop the skills and confidence they need to take control of their individual health issues and to take action with their neighbours on collective concerns. The breadth of interest in the determinants of health gives CHCs a platform from which to speak up on social issues that affect the community at large. Their closeness to the grassroots creates trust with community members and gives CHCs a knowledge and understanding of community health that is not always available to more traditional health providers and institutions. The flexibility of the CHC enables it to mediate between these traditional providers and other parts of the community in order to create opportunities for partnerships and cooperative action.

Observations

CHCs and Primary Care Reform

The Ontario Ministry of Health and the Ontario Medical Association have launched Family Health Networks as a means to improve primary health care delivery. So far community health centres have not been involved in the overall initiative. It may well be asked why this is so? On the face of it, the objectives of primary care reform and the CHC model are highly consistent.

- CHCs are accessible, geographically, culturally, linguistically and economically. CHCs don't just draw people to them, they also reach out. They are flexible.
- They provide comprehensive services in urban, rural and remote communities. In addition to physicians, nurses and nurse practitioners, they also generally have some staff support for social work, health education and community development. CHC multidisciplinary teams enable referrals within the centre so client issues can be addressed holistically.
- CHC clinical services are provided on a 24/7 basis, by their own staff or by sharing on-call duties with other CHCs in the same area or by setting up arrangements with other health agencies.
- Collaboration among CHCs, and between CHCs and other health and community partners, brings a range of service to their clients that would not be possible if the centres were each operating separately. Collaboration and partnership mean more effective use of scarce resources—funds, expertise, efforts.

- The strong health promotion and education component of CHCs helps people to better manage chronic conditions and increases their understanding of how to stay healthier longer.
- The focus on the determinants of health leads to a strategy of building the capacity of individuals and the community to take charge of their own health individually and collectively.
- Cost containment is achieved through global budgets, and cost effectiveness in terms of health outcomes for individuals and communities should be the result of primary prevention and health education.
- The accountability framework of CHCs through accreditation and program evaluation ensures the continued clear focus on the fundamentals of wellness, collaborative partnerships, and building individual and community capacity. This means that CHCs remain in and of the voluntary sector and responsible to their communities, as well as to their funders. The framework also provides the means to track health outcomes at both the individual and community levels in order to assure high standards of care and service responsive to community needs.

It is no surprise then that community health centres view their model as a logical part of any primary care reform initiative and, through their provincial association, have tried to press the point on its efficacy. In the fall of 2000, the Minister responded by announcing a Strategic Review to examine the strengths and limitations of CHCs as a means of organizing and delivering primary health services, as well as the opportunities and challenges in using CHCs as a vehicle for delivering on key Ministry strategies. The Strategic Review was completed in the spring 2001 and is now with the Minister's office for consideration. While the report is not yet public, there are expectations that the review will support the CHC model and lead to recognition of its contribution to primary care reform objectives.

In Eastern Ontario, there are two Family Health Networks—one in Kingston that is fully operational and one in the Ottawa area that was still in development at the time of the Ministry's Phase 1 Evaluation in March 2001. There are also 13 community health centres—in urban, suburban and rural communities, including one centre serving the French-speaking population of Cornwall and one serving Aboriginal people living in Ottawa. The proximity of existing CHCs to the Family Health Network pilot sites presents opportunities for assessing the two models on common ground, and learning more about their respective contributions to improvements in primary health care delivery.

Community Health Centres and the Priorities of Canada's First Ministers

The community health centre concept also supports the priorities of Canada's First Ministers. The First Ministers' Action Plan calls for improved access, strengthened investments in health promotion and wellness, improvements to primary health care through interdisciplinary primary health care teams, and clear accountability and reporting to Canadians. All of these objectives are consistent with the community governance model of the CHC, as well as its fundamental operating principles.

Why Then are CHCs Not One of an Array of Models Being Assessed?

Our focus on Ontario, in particular, points to several possible reasons. The initiatives for Primary Care Networks and Family Health Networks arose from discussions and negotiations between the Ministry of Health and the Ontario Medical Association. Therefore, the model is physician-centred and seeks to change billing practices from fee-for-service to some form of salary for physicians with capitation payments to the networks. The funds to support the initiative are drawn from the Ontario Health Insurance Plan, which presently pays for the vast majority of fee-for-service private practice family physicians. The focus is quite narrow even though it does provide some scope for nurse practitioners and other health professionals.

On the other hand, the CHC Program within the Ministry of Health is separate from the division of the Ministry that deals with physician services. This has been advantageous in many ways, because it has enabled CHCs to operate and develop their potential without competing for funds with the Ontario Medical Association. The fact that the Ministry provides ongoing support for more than 50 CHCs across the province indicates their interest and understanding of the benefits of the model. Nevertheless, at $100 million or less than one percent of the Ministry's total budget, total funding for the CHC Program is miniscule.

At a time when governments are trying to control costs and reallocate funds to more effective service models, the possibility of adding significant new funds to support CHCs in communities that want them is not likely to happen without some kind of reallocation from other Ministry programs. In that event, the CHCs could be seen to be competing for funds earmarked for physician services, among others. It is no secret that organizations representing physicians would not welcome a primary health care model that would move them towards salaried positions as employees in CHCs.

There may also be another factor at play. CHCs in most cases cover a geographic catchment area so that anyone who lives within the area can make use of their services. While the programs CHCs provide are broad in scope, they have been especially successful in reaching out to disadvantaged and marginalized populations—rural and northern communities that are unable to attract private practice physicians, urban Aboriginal people, the homeless, the poor, recent immigrants and refugees. There is now some concern that this success may "pigeonhole" the CHC model as only a service for "hard-to-serve" populations while the physician-based models are directed to the mainstream community. If these concerns were borne out, CHCs would only be seen as a model of primary care in situations where Family Health Networks do not come together. In effect, CHCs would be part of the reform almost as a last resort or for marginalized populations only, rather than being integral to the initiative.

Finally, there is not enough evaluation of how CHCs make a difference to clients and contribute to the more effective delivery of primary health care. This is perhaps a debilitating problem, since it leaves arguments for effectiveness on less than solid ground at a time when evidence of that effectiveness is needed to advance the model of care. An added challenge is that social/community development has always had difficulty providing quantitative evidence about its effects. Recent efforts to create a program evaluation framework and increasing demands for CHCs to be more accountable for the funds they receive have not yet brought dedicated funds for evaluation nor the in-house expertise needed to support it. Links to academic researchers are neither very strong nor widespread across the sector. If CHCs are to be seriously considered as a solution for primary care reform, more attention and effort will be needed on this front as well.

Conclusion: Community Health Centres— The Voluntary Health Sector at Work

The community health centres model, as practised in Eastern Ontario, is a model of the voluntary health sector at work. Strategic direction and accountability are grounded in community. Accountability for public funds is strengthened because CHCs are organized in law as non-profit corporations and may be registered charities. CHCs in Ontario use volunteers extensively, in board and committee work, program implementation, clerical and administrative support, and in program and volunteer coordination. Through these voluntary organizations, citizens add value through collaborating to meet community needs. Stronger communities and a stronger society are built.

For Further Research

The voluntary sector community health centres that were the subject of this investigation provide important examples of how organizations that are based in and accountable to the community can provide a key public service. The examples outlined above highlight the mix of community development, intersectoral action, collaborative mechanisms and front-line delivery of primary health care services that takes place through a community-centred organization that builds on determinants of health.

This investigation suggests that further research could improve understanding of the role the voluntary health sector plays in Canada and demonstrate its efficacy as part of the broader health policy debate. Some possible lines of inquiry include the following.

- Investigation into incentives for **collaborative efforts** such as those noted in the description above of CHC activities: what encourages, and discourages, collaboration?
- Descriptive research on **horizontal collaboration** across communities and sectors in health: what conditions in the community and in the individual organizations facilitate cooperative work? How can such conditions be fostered, and by whom?
- Descriptive research on **vertical collaboration** between local organizations such as CHCs with regional and national organizations in the voluntary health sector: what examples currently exist, and are there other opportunities around public issues such as primary care reform?
- Investigation into other voluntary organizations that provide public services: Children's Aid Societies in Ontario come to mind, as do hospitals and universities. How do organizations with a publicly assigned mandate balance off accountability for their legislated mandates with their voluntary structure?
- Examination of how CHCs and other voluntary sector health agencies make a difference and contribute to the health system as a whole. How do these models contribute to the objectives of a more accessible, responsive health delivery system that helps people and communities live healthier lives? What place should these models have in improving primary health care?

6. The Voluntary Health Sector:

Successful Advocates for Health Research Funding

Elinor Wilson
Heart and Stroke Foundation of Canada

Introduction

The voluntary sector in Canada is extremely diverse. While we have very limited information about the sector, it is estimated to consist of some 175,000 organizations, slightly more than 78,000 of which are registered charities.[1] These organizations vary considerably in size, budget, purpose, structure, approaches and funding sources. In addition, these organizations range across a host of areas, including social and community services, international activities, education and health, arts and culture, sports, religion, community and public foundations, and environment. While some organizations have multimillion dollar budgets, elaborate and sophisticated board structures, trained staff including paid professionals and an extensive network of volunteers, others have little or no budget at all and rely entirely on a handful of volunteers and past contributions from members and neighbours.[2]

As the diversity in its composition, size and activity areas suggests, the voluntary sector fulfils many functions: representation of groups and individuals who otherwise might not be heard by government, delivery of services not delivered by the government sector, and citizen engagement—a way for citizens to connect at a community level and work together toward overarching goals.

The role of the voluntary sector can be categorized as complementary, supplementary or adversarial.[3] This is dependent on what it is that the sector is attempting to accomplish at any given time. The adversarial role, or stated positively the advocacy role, is a well-known activity of the voluntary sector, and it is this advocacy role that is examined in this paper.

More specifically, this paper looks at a recent example of the vital advocacy role played by the charities that fund health research in Canada to help increase government funding to this health research. The paper focusses on the role of two organizations in particular, the Health Charities Council of Canada and the Council for Health Research in Canada.

After presenting some background theory on advocacy, and briefly demonstrating how Canada's health research expenditures were lagging behind in the late 1990s, this paper tells a story—the story of how advocacy was used by health charities to achieve real results for the benefit of all Canadians.

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[1] Hall M. and K. Banting. 2000. *The Non-Profit Sector in Canada: An Introduction.* Kingston School of Political Studies: Queen's University. Available online at **http://policy.queensu.ca/sps/ThirdSector/Papers/Hall-Banting/TheNonprofitSectorInCanada.html**.

[2] Good, D. A. 2001. "A Government Voluntary Sector Accord." *Isuma, Canadian Journal of Policy Research* 2(2): 46–52.

[3] Steuerle, C. E. and V. Hodgkinson, V. 1998. "Meeting Social Needs: Comparing the Resources of the Independent Sector and Government," Section II, Chapter 2. In Elizabeth T. Boris and C. Eugene Steuerle (eds.), *Non-Profits & Government: Collaboration and Conflict,* Washington, D.C.: The Urban Institute Press. Check online at **http://www.urban.org/pubs/npag/contents.html**.

Advocacy: Some Theoretical Perspectives

Throughout history, as civilizations and countries evolve, distinct groupings occur. A definition emerging in recent years of a "civil" society is this: for a country to be functioning at its highest level, a complex and delicate interaction among government, the non-governmental sector and private sector must occur. This balance must not only occur, but must also be valued and enhanced.

The voluntary sector, then, can be seen as one of three pillars of civil society. These three pillars are the public sector, the private sector and the voluntary sector. However, the interrelationships among these three pillars—the specific details of what these relationships are and what they should be—are the subject of debate.

In the United States, the debate about non-profits' role in advocacy is intense. And although the laws and contexts are different in Canada, it is useful to look briefly at American theory on advocacy because of the scrutiny it has been given.

Various theories on the role of groups in public life in America have been espoused, with corresponding theories on advocacy. Some analyses make distinctions between society-focussed advocacy and government-focussed advocacy. Other analyses make distinctions between direct and indirect advocacy. When it has to do with research, indirect advocacy may describe the participatory aspects of non-profit advocacy, particularly the capacity of groups to stimulate individual citizens to take action on their own behalf. In contrast, direct advocacy may refer to lobbying and other appearances before key decision makers by organizational representatives on behalf of others.

One of the most widely disseminated contributions to the debate in this area is contained in a draft statement of the Aspen Institute, an international non-profit educational institution headquartered in Washington, D.C. This statement, published in the fall of 2000, contained the results of consultations with business, government, academia, the media, non-profit organizations and foundations. In these consultations, one of the deliberations concerned the function of the non-profit sector and its role in promoting civic participation and advocacy. There were several points of agreement and disagreement. Advocacy was seen as a fundamental function, and active participation in the policy process a fundamental function of the non-profit sector in a democratic society, something to be encouraged in the future. It was observed that participation in the policy process can provide benefits such as focussing public attention on key social problems and solutions, increasing the base of knowledge on which sound innovative policy is formed, ensuring access for new and unheard voices, fostering governmental accountability to citizens, promoting democratic values such as freedom of expression, pluralism and self-sacrifice shaped by a vision of the public good, and giving citizens a personal sense of efficacy and civic skills as players in the democratic process, as well as increasing their sense of attachment to the community.[4]

In Canada, a joint initiative launched to improve and strengthen the long-standing relationship of the federal government and the voluntary sector released a report in 1999. In this

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[4] The Aspen Institute. 2000. *The Nonprofit Contribution to Civic Participation and Advocacy: A Draft Statement for Public Discussion.* Washington, D.C: The Aspen Institute. Available online at **http://www.aspeninst.org/nppf/pdfs/nssg.pdf**.

report, *advocacy* was defined as the act of "speaking, or of disseminating, information intended to influence individual behaviour or opinion, corporate conduct, or public policy and law. However, while the act of advocacy is merely a means to an end the nature of the public benefit which accrues needs to be considered."[5] The report identified problem areas for charities, including the boundaries between permissible charitable endeavour and impermissible political activity and between education and promotion of a point of view and the *Income Tax Act*, which has provisions limiting political activities by charities, and the Canada Customs and Revenue Agency's (previously Revenue Canada's) specific interpretation of the Act's provisions.

In general, the rules in Canada may be summarized as follows. Education must not amount to promotion of a particular point of view or political orientation, or to persuasion, indoctrination or propaganda. A charity cannot have political purposes, but it may devote some of its resources to political activities as long as they are non-partisan and they remain "incidental and ancillary" to the charity's purpose, and as long as substantially all (90 percent) of the charity's resources are devoted to charitable activities.

Canada's Investment in Health Research: A Comparison

Canada is fortunate to have a world-renowned health research community. It has developed and been sustained on a relatively small investment in research compared to other member countries of the Organisation for Economic Co-operation and Development (OECD). In the world ranking in gross expenditures on research and development as a proportion of gross domestic product for OECD countries, Sweden is ranked first at 3.85, the United States sixth at 2.6, and Canada comes in fifteenth at 1.60.[6]

In the United States, the National Institutes of Health increased their 2001–2002 budget for health research to US$2.5 billion. Figure 6-1 demonstrates a small improvement in per capita investment in health research and development in Canada; however, in comparison to the United Kingdom and the United States, Canada's per capita investments in health are still low (see Figure 6-2). Compared with selected countries from 1990 to 1997, the premier funding agency for health research at the time, the Medical Research Council of Canada, demonstrated negative growth (see Figure 6-3). Despite this, Laval University in Quebec and Mount Sinai Hospital in Ontario ranked first and tenth among institutions having the most citation impact (1994–1998) by the Institute of Scientific Information. There was no doubt in the health research community that Canada needed to invest significant dollars in health research. (Health research in Canada has been funded by many organization and agencies, ranging from hospital research foundations, to private foundations, provincial governments, health charities and national government institutions, such as the Medical Research Council of Canada.)

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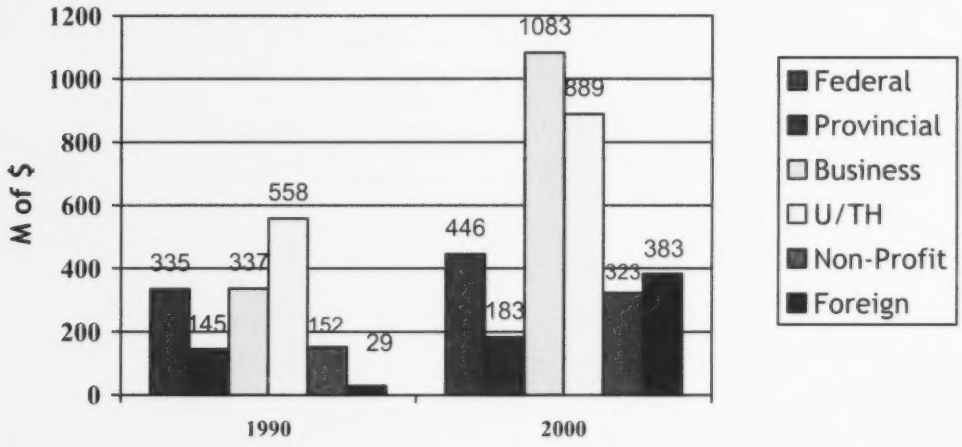
[5] *Working Together: A Government of Canada/Voluntary Sector Joint Initiative: Report of the Joint Table* 1999 (August). In June 2000, the Voluntary Sector Initiative was announced. A joint table made up of government and voluntary sector representatives was established to develop an accord. The Joint Accord Table developed a draft accord and broad consultations took place across Canada during the summer and fall of 2001. Check online at **http://www.vsi-isbc.ca/eng/joint_tables/accord** for more information on the accord, and at **http://www.vsi-isbc.ca/eng/reports_wt_exec.cfm** for the executive summary of the *Working Together* report.

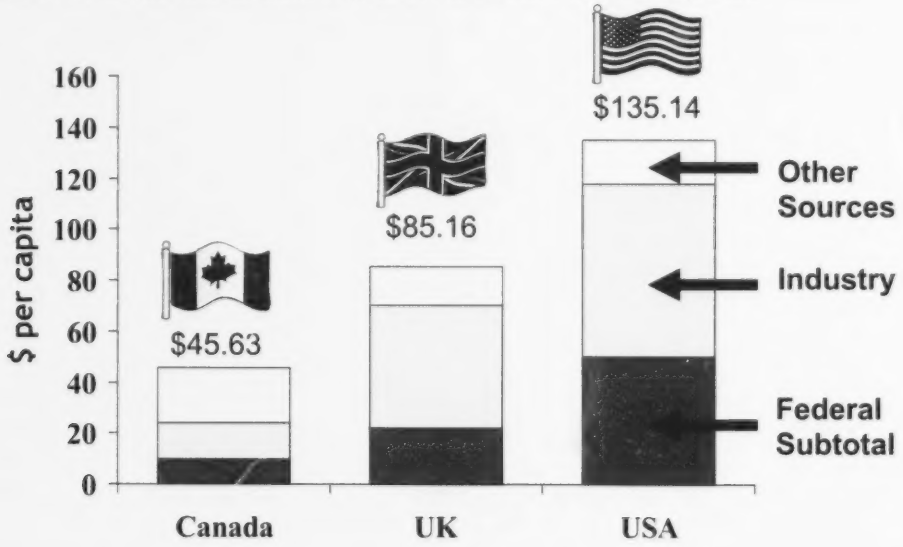
[6] OECD Main Science and Technology Indicators, 1997 Data.

Figure 6-1: Canada's Expenditures on R&D in Health:
Leveraging Improves From 1:5 to 1:7 in 10 Years



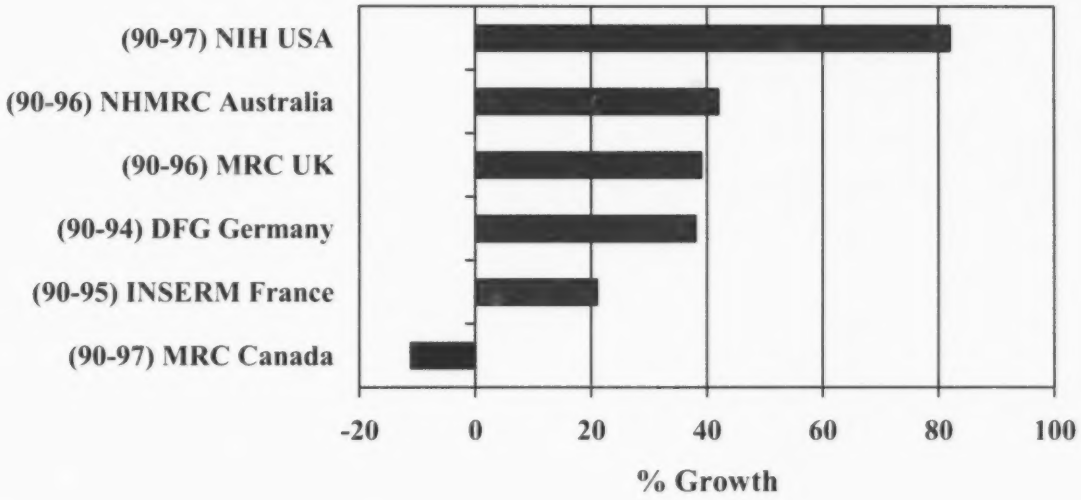
Source: Estimates of Canadian research and development expenditures (gross expenditures on research and development), Statistics Canada

Figure 6-2: Per Capita Investment in Health Research and Development



Source: Canadian Institutes of Health Research (see **http://www.cihr.ca**)

Figure 6-3: Canada's Health Research Budget Compared with Select Countries



Source: Canadian Institutes of Health Research (see **http://www.cihr.ca**)

Responding to the Challenge

The Medical Research Council (MRC) of Canada used to be the major federal agency responsible for funding biomedical research in Canada. Its role was to promote, assist and undertake basic, applied and clinical research in Canada in the health sciences. It also had a major role in supporting research training of health scientists and acted as an advisor on health research to the federal Minister of Health.

In 1998, it was apparent that Canada was lagging behind a significant number of countries in its investment in research and a paradigm shift needed to occur in the type of research funded.

The Government of Canada responded to this challenge by establishing a task force under the aegis of the MRC, representing the full spectrum of the research community. This task force proposed to the federal government a new, unique and made-in-Canada model for organizing and funding Canadian health research.

The health charities community in Canada, while on one hand being extremely supportive of the government's desire to increase the amount of funding to health research in Canada, had significant concerns about the meaning of this to the health charities sector in terms of its viability, especially in terms of fundraising.

As was already mentioned, there are more than 175,000 non-profit organizations operating in Canada, and close to 80,000 of these are registered as charities with the Canada Customs and Revenue Agency. Of these, the vast majority are classified as religious charities, with only 7.6 percent listed as health charities. Almost half of all charities in Canada report

annual revenues of less than $50,000. An additional third report revenues of $50,000 to $250,000. Only 19 percent have revenues of $250,000 or more, and only 2 percent have revenues of $5 million or more. Thus, the voluntary sector accounts for one eighth of Canada's gross domestic product, with an estimated $90 billion in annual revenues and $109 billion in assets. As well, the voluntary health sector allocates approximately $300 million each year to support health research. Clearly, the health charity sector makes a significant investment to health research in Canada, and as such, its concerns needed to be addressed.

Health charities' concerns focussed around several issues: 1) the impact that a significant government investment in health research would have on the public contributions to research funded by health charities, 2) the competition with government in terms of public visibility and credit for the funding of research, and 3) a concern that health charities with a much smaller research budget would only be able to fund smaller grants to researchers and not be able to fund "cutting-edge" work.

The major health charities, which funded approximately $300 million a year in research, came together in a loose affiliation to have input into this process. One of the first activities undertaken was an Environics survey of the public on its beliefs and values about the charitable sector partnering with government in joint funding of research.

This initial work provided assurance to the health charities that the public, which they were mandated to serve, would not see this as a competitive issue, but rather as a way that the governmental and non-governmental sectors could work together to leverage resources for health research in Canada. Non-governmental organizations mobilized quickly to promote increased funding for health research in Canada. The techniques used were a combination of advocacy and lobbying.[7]

What followed was a real-life demonstration of what the literature and theory on this subject describes as effective advocacy strategies—the ability to mobilize a broad grassroots movement or its equivalent, representation through an organized constituency, a good understanding of how governments function and how decision making takes place, a lobbying campaign, a legitimate claim on the public interest, an ability to frame the debate in terms that favour the desired course of action, and professionally sophisticated lobbyists.

The literature also describes how often this work is done through coalitions.[8] The advantages of coalitions are, for example, economies of scale, division of labour and reduced duplication, strength in numbers, a united front and consistency of message, a wider reach, a perception of broad community support, media control, an ability to reduce the risk of counterproductive activities, pooling of resources and cost efficiency. One of the challenges in mounting any advocacy or lobbying program is the ability to be there for the long haul. In advocating for increased research funding, the health community was able to demonstrate precisely these abilities and advantages.

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[7] For the purposes of this discussion, advocacy refers to the process of promoting certain positions or courses of action, usually implying a more specific process of influencing political decisions as they are made. Lobbying normally involves activities designed to influence or sway public officials toward a desired course of action.

[8] Utilizing a coalition approach is not new. Coalitions are often referred to as process coalitions and action coalitions. Process coalitions often consult around the issue to build ownership and are most suited for networking over a longer time frame with broader-based interests. Action coalitions, on the other hand, have a very narrow focus, a results orientation, and are most suited for public policy advocacy in government lobbying.

Many groups work individually in the campaign of increasing research funding in Canada. However, this paper deals with two major groupings that work closely together very effectively in this area despite their different mandates. These two groupings are the Health Charities Council of Canada and the Council for Health Research in Canada.

Spotlight on Two Organizations: The Health Charities Council of Canada and the Council for Health Research in Canada

The results of the original task force deliberations, which included representatives of three health charities, recommended the establishment of an organization in Canada that would become a much larger and more encompassing health research granting agency. The recommendation was to establish the Canadian Institutes of Health Research (CIHR), a family of virtual institutes organizing and funding health research in Canada.

As a result of this discussion, an Interim Governing Council (IGC) was formed. The IGC was a group of 34 distinguished scientists, leading academics, educators, health practitioners, social scientists and representatives from the voluntary and private sector who created a series of subcommittees to prepare working papers that would address key issues related to the CIHR. The health charities sector became an important part of the deliberations.

The IGC was co-chaired by the President and CEO of the MRC of Canada and the CEO/Executive Director of the Canadian Cancer Society and the National Cancer Institute of Canada. As well, to further the government's understanding of the contribution and role of the voluntary sector, the IGC included a volunteer representative of the Heart and Stroke Foundation of Canada. A staff person from one of the major health charities was seconded to the IGC on a part-time basis to provide direct input into the staff deliberations as they worked for the establishment of the CIHR.

The health non-governmental sector in Canada was also undergoing tremendous transition at the time, changing from a loose affiliation of health charities organized through the National Voluntary Health Association, part of the National Voluntary Organizations, to a more formal organizational grouping, the Health Charities Council of Canada. This group was formally established in June 2000 and was the culmination of the collective work of more than 35 national health charities. Its mandate is to provide a collective voice for national health charities on common issues and concerns and to come together to affect policy and the broad areas of interest of research, health information/surveillance and community/patient support.

The Health Charities Council of Canada quickly formulated recommendations to the federal government regarding health research funding. The policy platform in the health research area was to increase the A-based budget (regular funding approved by Parliament) of the CIHR to $1 billion annually over the next three years, increase funding to Health Canada by an additional $300 million annually for the next five years to better respond to the health needs of Canadians, and enhance the tax measures for modest donors to any registered charity (individuals whose combined donations are $2,500 a year or less).

The Health Charities Council of Canada, by defining health research as one of its major priorities through consultations with all its memberships, built a feeling of ownership for this issue. Staff in Ottawa made presentations before parliamentary standing committees on health and finance. The Health Charities Council participated in meetings on Parliament Hill with

federal members of Parliament. At these meetings, the joint strengths of the health charities were demonstrated. The presence of individuals who could relate the personal effects of health issues to the members of Parliament, coupled with the presence of scientists able to reflect what increased health research dollars would be able to do in terms of managing these issues, provided a very powerful framework and background for members of Parliament. The Health Charities Council also had direct meetings with members of Parliament in their ridings and constituencies, which proved to be a very effective grassroots approach.

The Council for Health Research in Canada is a national not-for-profit organization comprised of health agencies and research institutions with lay boards of directors that raise funds for health research. The Council was established in 1996 to influence the Canadian public and private sector through various strategies on the effect of increased funding for health research. This Council is an example of an action coalition: it was formed specifically to lobby around increasing funding for health research in Canada.

The current platform adopted by the Council for Health Research in Canada is a platform of $1 billion for the CIHR as a worthwhile investment for government. This represents less than one percent of current health care expenditures and this amount of dollars would further advance broader government priorities, stimulate an effective biotech and life sciences knowledge-based economy, reduce the economic burden of illness in Canada, develop an innovative, cost-effective and evidence-based health care system, and brand Canada as the place to be for health research in the 21st century. This lobbying platform of the Council for Health Research in Canada built on the direction proposed by the IGC in promoting the establishment of the CIHR.

Results

It is always difficult not only to measure results but also to attribute results in these types of arenas to specific actions. However, both the Council for Health Research in Canada and the Health Charities Council of Canada did play a vital role. In the 1999 federal budget, there was funding of $550 million over three fiscal years for new research initiatives, the establishment of a task force as described earlier under the aegis of the MRC representing the full spectrum of the research community, and a task force recommendation to establish the CIHR. This sustained, ongoing involvement and presence of these groups over the long term played a role in the establishment of the CIHR.

In 2000, the Government of Canada passed Bill C-13. Entitled the *Canadian Institutes of Health Research Act*, this Act established the CIHR, repealed the *Medical Research Council Act* and made consequential amendments to other laws. The new Act states that CIHR will engage voluntary organizations, the private sector and others in or outside Canada with complementary research interests. It also states that CIHR will communicate with the public, governments and the Canadian international research communities, voluntary organizations and the private sector on issues pertaining to health or health research.

For Further Research

Despite the examples of successful lobbying in the Canadian context and our belief that in the example just outlined the lobbying conducted to increase research funding was successful, there remain outstanding research questions in the area, including:

- the relationship between advocacy and effectiveness in achieving exempt purposes;
- the effectiveness of different types of advocacy;
- how organizations create an advocacy capacity;
- the rationale for government to limit advocacy activities;
- whether non-profit status and/or tax exemption is necessary for organizations to play effective roles as intermediary associations;
- an identification of the necessary resources required for advocacy; and
- an identification of what kind of research and information are most useful to legislators or administrators for decision making.

Conclusion

Susan D. Phillips, in her paper "Voluntary Sector: State Relationships in Federal Systems," observes that in most democratic countries there is a fundamental change taking place in the relationship between government and the voluntary sector. This is not because one or the other is changing—in fact, both the nature of governance and the voluntary sector are changing. Phillips says:

> Governments of both the left and right are also taking renewed interest in citizenship: in promoting voluntarism, an active citizenry and a vibrant civil society. The result has been a realization on the part of governments that they need the voluntary sector more than ever, not only as partners in service delivery, but in building social capital and enhancing social cohesion. On the other hand, the voluntary/non profit sector is evolving rapidly from a model based on charity to one based on civil society—that is, from a model premised on helping those less fortunate to one in which communities have resources and are empowered to represent and help themselves. This has sparked the emergence of strong national leadership aimed at providing strategic direction to the sector and the demands for new policy tools and citizen engagement in processes… The diversity of the voluntary sector should neither be underestimated nor ignored. Indeed, diversity is the sector's underlying strength, allowing flexibility in meeting a wide range of community needs, enabling representation of an enormous variety of particular communities and creating multiple routes of citizen access to collective action.[9]

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[9] Susan D. Phillips, *Voluntary Sector: State Relationships in Federal Systems*. Available online at the Forum of Federations site: **http://www.ciff.on.ca/References/documents/bg_papers/docbg_phillips.html**.

By presenting this brief overview of how effective the voluntary health sector is becoming as an advocate for health research in Canada, this study has made two major points.

First, the important role of the voluntary health sector in advocating for improved funding for health research has been demonstrated.

But also, as described in the introduction to this paper, the voluntary sector in Canada is large and diverse. Given the positive health consequences for Canadians that potentially result from the voluntary health sector's advocacy in this area of health research funding, and the fact that this is only one of its vital contributions, the true value of the voluntary health sector in particular and the voluntary sector in general to the quality of Canadian life must be enormous. One of the challenges we are faced with is that it is also largely uncharted and therefore unknown.